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ABSTRACT

This annotated bibliography provides approximately 100 summaries and evaluations of documents, published from 1979 to 1995, on personal assistance services (PAS) for individuals with disabilities. Studies and articles were selected for inclusion based upon their capacity to inform the development of PAS models, including conceptual, policy, and practice features. Studies are analyzed according to three dimensions of service provision (degree of consumer control, degree of individualization and personalization, and degree of community membership) based on a policy model stressing support and empowerment. In relationship to this policy model, primary features of concern are systems/policy, access, eligibility, assessment, services limitations, workforce issues, liability, service quality, long term services coordination, and consumer control. The summaries and analyses are grouped into those on personal assistance in the fields of: (1) brain injury, (2) mental retardation and physical disabilities, (3) psychiatric disabilities, (4) technology assistance/dependence, and (5) youth with disabilities. An appendix relates the reviewed literature specifically to a policy model proposed by Simi Litvak of the World Institute on Disability. Indexes by author, organizations, and subject are provided. (Author/DB)

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COMMUNITY AND POLICY STUDIES

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PERSONAL ASSISTANCE SERVICES (PAS): TOWARD UNIVERSAL ACCESS TO SUPPORT

Annotated Bibliography

May 1995

Prepared by:
Julie Ann Racino
Community and Policy Studies

Prepared for:
World Institute on Disability
Oakland, California

The New Models Development Research Project was designed to identify potentially best practices, including consumer-directed program models, to serve populations for whom best practices cannot be identified because so few programs actually serve these people or have designed any particular response to their service needs, including those with combined physical and cognitive disabilities, brain injuries, psychiatric disabilities, communication disabilities, technology dependency, youth and members of ethnic groups.

This annotated bibliography contains selections in the categorical areas of brain injury, youth with technology needs, psychiatric disabilities, youth with disabilities and mental retardation and physical disability, and was prepared with partial support from the World Institute on Disability, Oakland, California to Community and Policy Studies. This work was made possible through the support of the National Institute on Disability and Rehabilitation (NIDRR grant #H13340005-95), in the Office of Special Education and Rehabilitation Services (OSERS), Department of Education. No endorsement of the World Institute on Disability, or US Department of Education should be inferred.

Community and Policy Studies is founded upon the belief that the full participation of people with disabilities, low incomes, diverse cultural and ethnic backgrounds, and of ordinary citizens in society requires a strong commitment to diversity within our communities.

Community and Policy Studies offers a variety of collaborative services ranging from program evaluations, technical assistance, field research studies, literature and informationreviews, state policy and practice analyses, support for non-writers, and the development of a range of practical and theoretical materials.

This document is offerred as new source material in the ongoing study of personal assistance services (PAS). Publications of Community and Policy Studies include newsletter articles, monographs/edited collections, journal articles, bibliographies, white papers, resource lists, and book chapters, inclusive of people with diverse disabilities.

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1997

Personal Assistance Services (PAS):
Toward Universal Access to Support

Julie Ann Racino

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Annotated Bibliography[1]

Personal Assistance Services: Toward Universal Access to Support

Personal assistance services (PAS) has been one of the rallying cries of people with disabilities, as a way for the Americans with Disabilities Act (ADA) to become a reality in work, schools, homes, businesses, and community, social, religious, economic and political life (e.g., Consortium of Citizens with Disabilities, 1991; DeJong, Batavia, & McKnew, 1992; Litvak, Zukas, & Heumann, 1987), and is also reflected in international policy (e.g., United Nations, 1993). PAS is part of the movement toward support in diverse environments (e.g., Racino, in press; Nisbet, 1992; Nosek, 1991) and the support paradigm (e.g., American Association of Mental Retardation, 1992; Racino, 1992), and the self help movements (Deegan, 1992; Zola, 1987). More recently PAS has received attention in the fields of mental retardation, mental health and brain injuries (e.g., Evans, Martinez, & Hopkins, 1992; Nosek, 1990 for National Council on Disability; Racino, 1991; Watson, 1991).

This annotated bibliography is one of the steps in the development of a conceptual model toward universal access of personal assistance services (World Institute on Disability, 1993) and support (e.g., Bradley & Knoll, 1993; O'Brien, 1992; Taylor, Bogdan & Racino, 1991), with the personal perspectives of people with disabilities informing public policy and practice. In particular, the bibliography highlights selections from the literature on children, youth, and adults with psychiatric disabilities, mental retardation and developmental and physical disabilities, technology needs, and brain injuries and their families. Designed as a companion piece to the "New Models" (categorical) reports, the bibliography offers insights into the salient features of these forthcoming developments.

Studies and articles were selected for inclusion based upon their capacity to inform the development of pas models, including conceptual, policy and practice features, which were also analyzed according to the three dimensions of service provision (Racino for WID, 1993) which underlies a support/empowerment approach (degree of consumer control, degree of individualization and personalization, and degree of community membership) In relationship to the policy model (Litvak for WID, 1993), primary features of concern are systems/policy, access, eligibility, assessment, services limitations, workforce issues, liability, service quality, long term services coordination, and consumer control (See appendix A).

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[1] *With only a few exceptions, the articles included here have not appeared in previous annotated bibliographies on pas or on community integration.*

* PERSONAL PERSPECTIVES:

- *people with disabilities on personal assistance services (pas), support services, and their own lives;*
- *consumer and self-help perspectives and movements (e.g., People First, "mental patients liberation");*
- *parents' perspectives on assistance and their lives;*
- *role models.*

* CONCEPTUAL ARTICLES:

- *pas and youth and their families (e.g., youth development, youth movements);*
- *model features (e.g., choicemaking and autonomy);*
- *pas in context of family services (family support, childrens' mental health, family-centered care);*
- *pas within the context of health care (e.g., health prevention);*
- *pas within the context of relationships and diverse cultures (ethnicity, class and gender embedded);*
- *critical issues (e.g., alcohol abuse).*

* PRACTICE AND ASSISTANCE

- *personal assistance or attendant care practice (e.g. self-management, instructional strategies, service roles);*
- *literature and research reviews on conceptual model issues (e.g., family support, health needs) as well as embedded reviews in articles;*
- *provider resources on pas and assistance for people with "cognitive" disabilities;*
- *legal issues in assistance (e.g., youth confidentiality);*
- *consumer (initiated, directed) support services.*

* PROFESSIONAL PRACTICES

- *prevalent and significant rehabilitation approaches in the categorical disability fields (e.g., psychiatric rehabilitation, cognitive rehabilitation) and support classifications.*

* SYSTEMS, COMMUNITIES AND POLICY

- *articles across life areas (e.g., employment, recreation, community living/home) with a focus on support and support services and transition;*
- *ADA and reasonable accommodations;*
- *systems and policy in support of people primarily with cognitive disabilities (e.g., long term care services and financing).*

* RESEARCH STUDIES

- *pas, housing and support, lifestyle planning, in-home supports, life course and experiences, parents'perspectives, health care services and systems, family support systems design, employment and school inclusion).*

** CONCEPTUALIZATION OF PRACTICE, PROGRAMS AND POLICIES*
- best practices in self advocacy and empowerment;
- innovative programs and policies for youth at-risk.

These annotations did not duplicate any of the major policy studies on PAS in the context of national health care reform, or agency home care at either the policy (inclusive of financing) or the practice levels, or any PAS related to elders and newborns. Pas within communities ("as a part of air"; Nosek, 1989) and as part of community organizations (recreation in neighborhood centers) (Racino & Williams, 1994) were not the primary priority for this review.

Research studies included quantitative and qualitative data-based (single and multiple) case studies, quasi-experimental designs, focus groups, qualitative in-depth participant observation, field interview studies, national and regional surveys, intervention studies, and multi-level state and cross-state studies.

The annotated bibliography is organized around five sections by categorical group selected by the World Institute on Disability as "underserved populations" with PAS: brain injury, mental retardation and physical disabilities, psychiatric disabilities, children and youth with assistive technology needs, and youth with disabilities. An Appendix highlighting contributions to the PAS Independent Living policy model is attached, together with an index by author and subject.

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TOWARD PERSONAL ASSISTANCE SERVICES IN FIELD OF BRAIN INJURY

Personal assistance services (PAS) are available in states, such as Kansas, for adults with brain injuries, with substantial barriers still existing for user-directed approahces. In the rehabilitation context, PAS are also a component of "self-directed care models" (e.g., Chriastensen et al, 1993), while only recently have the "non-therapeutic family support services been promoted in brain injury (Racino, 1995).

This section is organized around:
** two personal perspectives on brain injury (inclusive of the use of pas),*
** a qualitative study of the lives of people with brain injury,*
** a study of the needs and concerns of parents of children with brain injury,*
** two physical medicine and rehabilitation chapters (inclusive of functional impairments and the self-management of attendant care),*
** annual research indexes on brain injury (inclusive of cognition, assessment and funding),*
** an article on one type of service role (life coaches) paid through insurance;*
** an article on supported employment and monograph on education students with traumatic brain injury;*
** an editorial on model systems of alcohol abuse; and*
** two on public policy (inclusive of long-term care services and financing)[2].*

***Citation:** Watson, S. (1991). Pas and head injury. In J. Weissman, J. Kennedy, and S. Litvak (Eds). Personal perspectives on personal assistance services. Oakland, CA: RTC on Public Policy and Independent Living, World Institute on Disability.*

Summary:

One in a series of essays prepared for presentation at the International Personal Assistance Symposium held in Berkeley, California in 1991, this article represents one of the first accounts by a person with a disability of how a person who happens to have a head injury can use personal assistants in his or her own lives. Illustrating through her own life, she believed that potential areas for expansion of personal assistance services were in assistance with emotions, memory, daily structure, fitness/physical needs (e.g., joining a health spa), transportation (driving to programs), organization and decisionmaking.

The article also highlights specific critical points related to the use (or employment) of personal assistants: (1) as a substitute for casemanagers; and (2) for the performance of tasks

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[2] The review does not include evaluations, for example, of personal assistance services in states such as Virginia, or of financing (e.g., targeted Medicaid waivers) in states such as Minnesota.

such as cuing, structuring of the day, organizing and reminding in ways that a personal (work) assistant might do. The author describes the difficulty in training a personal assistant in the essential area of "emotions" and how personal assistants can act like "coaches" to "help assess the situation (e.g., meeting) afterwards and to engage in activities such as role plays."

Analysis:

The essay offers new insights and perspectives not previously written about by a woman with a head injury on personal assistance services. As part of the monograph, reflecting essays by youth and adults with disabilities, and their parents, Sherri Watson introduces the reader to user-directed pas by adults with "head injuries." No descriptions of children, youth or families are included in this particular essay.

Contributions to Conceptual Model:

Each of the critical points mentioned in the summary also reflect central issues in the design of personal assistance services, including moving from a monitoring role of assistance (e.g., casemanagement), the roles, if any, an assistant may play in social and emotional areas, the "cognitive" tasks which an assistant may do and the style in which these tasks are done, and the distinctions, if any, between the roles of job coaches and personal assistants in employment.

Keywords: *personal assistance, rehabilitation, community supports, brain injury, cognitive disabilities, employment*

Citation: *Bergland, M. & Thomas, K. (1991). Psychosocial issues following severe head injury in adolescence: Individual and family perceptions.* ***Rehabilitation Counseling Bulletin****, 35(1), 5-21.*

Summary:

One of the few qualitative research articles available, "the purpose of the study was to identify the problems, issues and experiences of adolescents (ages 13 to 18) with severe brain injuries and their families in five categories (i.e., self, family, friends, school and work)." The findings of both the "caregivers" and the "adolescents'" perspectives are presented; for example, changes in people's relationships, in academic and extracurricular areas, a lack of understanding and assistance. The authors discuss their findings in the context of individual ("personal constructs") and family issues ("role and status in family and community"), "social skills" and "social isolation", and vocation, transition and independent living (e.g., autonomy issues as presented by Wehman & Kreutzer, 1990).

Analysis:

The authors interpret their data in the context of "models stressing coordination and *flexibility" and "maximum autonomy" with an awareness of alternate lifestyles, including attention to a broad range of "community functioning" (i.e., school, social, leisure and vocational)" which are viewed as consistent with both the Independent Living and Transition Models[3]. The research study is important to pas development, in part, because it attempts to represent the person's perspective as well as the caregiver's. Specifically, the article decribes how the person and their parents experience the effects (primarily "problems" such as the loss of friendship) of the brain injury (whether in themselves, other people, places or services).*

Contributions to Conceptual Model:

Life experiences of people with brain injuries in this study are based on changes in people's relationships (environment) and how people come to view themselves in relationship to others (inclusive of career, friends and family). The article offers specific suggestions regarding "program" areas to address (e.g., reduction in time spent with insurance forms, financial strain, reduction in time and expense of transportation). However, the article's primary contribution in relationship to pas is in its creation of a picture of growing circles of losses in a person's life, thus opening the door for personal (autonomy-based) and community (prevention) forms of pas.

***Keywords:** psychosocial functioning, adolescence, autonomy, caregivers, independent living, qualitative research, transition, vocational rehabilitation, career development, social relationships, coping strategies, social skills, peer groups, community services*

***Citation:** Biscup, K. (1990). Survival, struggle, & success: comprehensive rehabilitation of traumatic brain injury[4]. Journal of Rehabilitation, 11-13.*

Summary:

This essay briefly shares a "success story" (as defined by the author) of her redirection and refocus of her life plans after a car accident, and the author's overview of head injury, rehabilitation and independent living. She was in a coma for 12 weeks after a closed head injury, and obtained "independent living skills training" at a Washington Medical Center. After moving to her parents' hometown in Montana, she completed a master's degree in human services and received an award for the "design and successful management of comprehensive rehabilitation." She credits the rehabilitation practitioners and her parents with their role in her "victory" in "beating the odds."

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[3] *Model development tends to be aligned with replication theories, which are incompatible with theories on innovations.*

[4] *For other accounts by and on survivor issues, see the educational catalogue of the National Head Injury Foundation (1993), which also includes treatment and rehabilitation issues, education, family issues, research, economic impact, advocacy, life care planning, legal and ethical issues and casemanagement.*

The author views independent living as a "specialty" which is "derived from the coordination of the medical model of traditional acute-care rehabilitation services and community-based services." The three principles on which IL is based, according to the author, are consumer sovereignity, self-reliance, and political/economic rights. She views the goal of rehabilitation as maximizing "independence through mastery of physical, linguistic, cognitive and psychosocial skills." Expertise is viewed as being able to be delivered by the "client" through "managed plans." In order for independent living theory to be translated into reality "by promoting appropriate support services, accessible environments, and pertinent information and skills," "persons with disabilities need to be accepting of treatment."

The articles end with recommendations for "coping with stress": taking careful, frequent inventories of self (e.g.. through a journal), sharing responsibility, exercising regularly, and maintaining a sensible well-balanced diet. She views stress as a "misunderstood concept" and as able to "strengthen defenses, stimulate greater productivity, and sharpen resolution."

Analysis:

Appearing in a professional, peer reviewed journal, this author contributes her personal perspective ("story") to the brain injury survivor literature. Her definitions of independent living, and the goals of rehabilitation vary from those espoused by the IL (independent living) movement, providing a good discussion base for the relationships among the medical model, community-professional based rehabilitation models, and the consumer movement. Her view of stress and coping is consistent with that of professional authors in other disability areas, which seeks to move from negative views of "conditions" toward models based upon contributions and strengths.

Contributions to Conceptual Model:

Of particular importance for the development of PAS are the perceived role of the "client" vis a vis "treatment", the skill-based view of independence based upon professional interventions and "managed plans", the "absorpt"ion of the client expertise "in a cooperative manner," the possibility of co-optation by professionals of the independent living model, and pas models based upon "contributions" and "strengths" versus negativity and adverserial relationships.

***Keywords:** head injury, rehabilitation, independent living, coping and stress, self-help*

***Citation:** Rosenthal, M. & Mayer, N. (1994, June). Special public policy issue. Journal of Head Trauma Rehabilitation, 9(2).*

Summary:

This special issue on public policy on persons with traumatic brain injuries and their families covers the range of issues from vocational, community living, long-term care and support services, state policies, ethics, education, clinical research, integrated rehabilitation systems in

New York, medicolegal and ethical to personal perspectives. "Head injury" programs are highlighted from the states of Massachusetts, Missouri, Minnesota, Kansas, Florida, Virginia and New York. Financing for long-term care services (Medicare, Medicaid, and private health, long term care, workers' compensation, and automobile insurance, state trust funds) and long-term vocational rehabilitation services (e.g., Job Training Partnership Act, Plan to Achieve Self-Support, Carl D. Perkins monies, private foundations) are discussed together with existing legislation and legislative proposals.

Analysis:

The articles do not use a common policy analysis framework, but provide one of the first journal overviews of the critical issues facing the developing field of traumatic brain injury. Presented from a disability policy and services practices viewpoint, as contrasted from a research perspective, these articles identify the essential long-term care elements for movement toward more-user directed personal assistance systems.

Consumer or service user perspectives are primarily included in the journal account of the National Head Injury Foundation and in excerpts of people's lives. One author expressed a common concern that the "independent living model" of consumer-directed services "by itself fails to take account of the special needs of many persons with mental impairments, including tbi."

The articles do not include a comparison of existing personal assistance services systems in states, with those designed for people with traumatic brain injuries. However, a relevant discussion of long-term care issues (e.g., expansion of eligibility of criteria for people with "cognitive impairments") and financing for support services and PAS are included.

Contributions to Conceptual Model:

Particular long-term care and support services' issues relevant to PAS development are: (a) the O'Keefe article (LTCSS as a disability issue, eligibility and tbi, 54-56), (b) the continuum basis for service design (e.g., Digre et al, 15) and "transitional services" (Kansas HCBS waiver, 45) for people with traumatic brain injuries[5], (c) the state program designs[6] inclusive of the Massachusetts program under the state's independent living division, (d) the timing of efforts to

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[5] *See Taylor, Racino, Knoll & Lutfiyya (1987) for analysis of the problems with the continuum as the basis of service design. Transitional services in the "residential" area have also been interpreted to mean the lack of permanent and stable housing, the need for people to move from one home or facility (and new neighbors and neighborhoods) to another based on externally imposed criteria, and the lack of availability of supports in one's own home.*

[6] *Also, see Wright, B. (1993) describing the status of development of the field of brain injuries in the U.S.*

repatriate people with tbi from other states (e.g., New York), (e) the relationship of paid and informal support services and PAS (inclusive of person-centered planning)[7]*, and (f) the use and implications of already existing specific financing for PAS (e.g., "recreation" from family support programs and PASS for work-related personal assistance) are all relevant to PAS model development.*

***Keywords:** traumatic brain injury, development of public policy, state program models, public policy, (vocational) rehabilitation, community supports, housing, personal assistance, community living, long-term care, long-term financing, long-term care legislation, long-term care policy, supported employment, rehabilitation technology, grass roots advocacy, policy/systems change.*

***Citation:** Wehman, P., Kreutzer, J., Sale, P., West, M., Morton, M. & Diambra, J. (1989). Cognitive impairment and remediations: Implications for employment following traumatic brain injury.*[8] ***Journal of Head Trauma Rehabilitation**, 4(3), 66-75*

Summary:

The purpose of the article is to provide a "rationale for developing cognitive remediation and compensatory strategies in the workplace," which do not rely on "generalization" from one setting to another. The authors briefly review the status of the head injury and employment literature (e.g., high rates of unemployment) and the role of "neuropsychological tests" in the return to work of people with head injury.

After describing the cognitive problems identified through their questionnaire of 37 "head-injured clients" (e.g., difficulty making decisions, thinks and reads slowly), the authors introduce their definition of cognitive remediation, the goals of therapy, and contrast "skill-training" models with "strategy-substitution" models. A detailed employment case history is presented, together with suggested compensatory strategies. The authors conclude by stating that "ideal programs are holistic and focus on a variety of issues, including family support, education, substance abuse, self-awareness, interpersonal behavior, effect of emotional adjustment, and recreational pursuits."

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[7] *Perspectives related to "support" in the fields of mental retardation and developmental disabilities varies from those in the field of independent living on the relationship between informal and formal (paid) services.*

[8] *See also, other publications on brain injury and employment by the authors including Kreutzer & Wehman (1990) on community integration following traumatic brain injury, on model systems of alcohol abuse following traumatic brain injury (e.g., Kreutzer & Harris, 1990), on public policy (e.g., Goodall, Lawyer, & Wehman, 1994), and on the Americans with Disabilities Act (1993).*

Analysis:

The article is an introductory piece, and brings together expertise in brain injury and cognition, with competitive employment approaches in "naturalistic" settings. Framed from the assumption that people with significant brain injuries can work in regular employment settings, the article attempts to address the primary "cognitive" impairments cited as "primary reasons for employment failures" (e.g., "forgets people's names", "loses track of time, day and date," and "loses train of thought") by suggesting specific compensatory strategies which may also be used in the workplace (an area where such adaptations and strategies had not been well explored).

The article reframes therapy in the context of "real world" environments ("the ultimate goal of therapy is to improve the individual's ability to function in work, academic and community living environments.") The detailed case study approach, which incorporates both skill training and compensatory strategies, is a useful counterpoint to personal accounts by survivors in PAS model development.

Contributions to Conceptual Model:

Specific strategies listed are: use of task analysis, visual cues such as checklists, written instructions, use of familiar phrases, verbal rehearsals of problematic situations, small notebooks, reducing distractions in work environment, watches and electronic devices as reminders of daily events, use of computers. These same strategies may be one that people with disabilities may use themselves.

***Keywords:** cognitive remediation, brain injury, employment, rehabilitation, neuropsychological tests*

***Citation:** Arokiasamy, C., McMorrow, D. & Moss, G. (1994). The tbi annual research index: Volume two (for 1990-91 publications). Orlando, Florida: Paul M. Deutsch Press.*

Summary:

These two annual research indexes organize research journal articles in brain injuries into the following areas: POST-ACUTE: assessment, outcomes and predictors, cognition and communication, neuropsychology, psychology, behavior (behavioral, neurobehavioral, pharmacological), psychosocial (social skills and psychosocial issues, sexuality), vocational (evaluation, rehabilitation and return to work, supported employment), physical functioning, medical management, case management and rehabilitation aspects (theoretical and practical), ethics, law and funding, family, pediatric and adolescent head injury, mild head injury and post-concussion syndrome, other (ADLs, driving, prevention, sports, substance abuse), miscellaneous/classics; and ACUTE: epidemiology radiologic technology, neurology & neurosurgery, medical, drug therapy, neuropsychological, physical functioning, coma and concussion, penetrating wounds and local lesions, pediatrics, mild head injury, case management *and rehabilitation aspects. Volume 1 contains over 1500 entries, Volume 2, over 2,000 entries, from almost 400 journals.*

Analysis:

The field of brain injury includes a "large volume of" research and to some extent, professional "conceptual articles, bibliographies, editorial and opinion papers, conference proceedings and workbooks." These research indexes are useful resources in identifying key areas to reflect in future PAS community and services research and development (e.g., assessment and cognition) in a field that is heavily clinically dominated in its research focus. They also provide a clear indication of the distinctions that need to be made between research knowledge and that which is applicable within the service domain.

Contributions to Conceptual Model:

For the development of pas models, specific model elements (e.g., "assessment," "casemanagement,"), age components of the model (as reflected in pediatric and adolescent head injury versus adults), the role of cognition and communication in decisionmaking, the roles of assistants (e.g., in relationship to "behavior" and emotions), major related issues (e.g., substance abuse, medical needs), financing ("funding") and model development across work (i.e., "vocational"), recreation (i.e., sports), and homelife ("ADLs") require a comparison with currently accepted practice.

Keywords: *research indexes, brain injuries, (vocational) rehabilitation, community support, personal assistance, pediatric and adolescent head injury, family support, mild head injury*

Citation: *Jones, M., Patrick, P., Evans, R., Wulff, J. (1991). The life coach model of community re-entry. In B. McMahon & L. Shaw, Work worth doing. Orlando, Florida: Paul M. Deutsch Press, Inc.*

Summary:

The article describes a life coach model for the "community reintegration of individuals with acquired brain injury" which is based upon the "principles of behavioral learning technology and their application to community-based instruction" (e.g., Horner, Dunlap & Koegel, 1988). The model uses (1) an "integrated treatment approach" in which the therapist acts as a consultant and enlists family members and other clinicians to assist; (2) direct instruction techniques to teach daily living skills; (3) clinical casemanager who "manages" the client's rehabilitation; (4) individualized treatment and application in the everyday world; and (5) an additional component to teach the client how to access continuing support services in the community. The goal is "to assist the client in acquiring the self-management skills he or she will need in successful community living, "gradually turning over responsibility from the casemanager."

Analysis:

The article is a good contribution to the direct service literature on the relationship between professsional and paraprofessional staff and people with disabilities. In relationship to user-directed pas, the professional model described is consistent with clinical management approaches to teaching "self-management"; however, all decisions regarding the treatment are those of the life coach who takes professional responsibility for assuring "the client doesn't become too dependent" and that the life coach adopts different "management styles" over the course of the "treatment." Self-management is also defined by the professional as are the "client outcomes." The life coaches work for the organization which is responsible for providing the treatment (life coaches get "respite").

Contributions to Conceptual Model:

The status of development of community services and the reimbursement of these services (for example, by insurance companies) were still relatively new at the time the article was written (with resistance to paying for regular home and community services a matter of concern). The life coach model is distinctly different from user-directed models of PAS, even in relationship to people with "severe injuries," primarily because of its top-down, professional management design and the practical implications of this design in moving to community life.

The concepts of respite for workers needs to be translated back to paid leave and vacations, just as the concept of respite as relieving caregivers of the "burden" of their children, needs to be translated into the regular breaks of children growing up (e.g., recreational activities and friendships separate from each other). For PAS, movement toward user-determined outcomes is critical, with nonprofessional supports or assistance, instead of a professional "treatment" focus.

***Keywords:** community re-entry, head (brain) injury, rehabilitation, community reintegration, treatment, daily living skills, self management*

***Citation:** Kreutzer, J. & Harris, J. (1990). Model systems for alcohol abuse following traumatic brain injury. **Brain Injury**, Vol. 4(1), 1-5.*

Summary:

As an editorial in one of the leading brain injury journals, the authors argue for the need for prevention, education, program and policy development for the "special population" of people with brain injuries who are alcohol abusers. Citing the absence of literature regarding assessment and treatment of alcohol abuse for persons with tbi, the authors explain that it was only in the mid-80s that surveys were conducted of rehabilitation treatment programmes regarding their policies related to alcohol consumption. In the early 1990s, the National Head Injury Foundation released its white paper on the effects of alcohol and treatment resources.

The editorial lays the groundwork for a proposed comprehensive model for treatment of alcohol abuse problems for persons with traumatic brain injury (Langley, Lindsay, Lam & Priddy, 1990) described in this journal. It cites research on the relationship between alcohol abuse and community adjustment, on the potential to reduce the costs of rehabilitation, on the (ab)use of alcohol in vocational rehabilitation and independent living programmes, on the use of diagnostic (e.g., DSM-III-R) classification systems and assessments (questionnaires, interviews, data history pre and post-injury), on the use of relatives in monitoring substance abuse programmes, on the need for educational programmes for professionals and other groups such as Alcoholics Anonymous, and group education on written policies.

Analysis:

The editorial is valuable in integrating a number of research, policy and treatment (as distinguished from service) areas into a call for programme development and education regarding a "population"[9] of people whose multiple concerns have not been well addressed within the rehabilitation context. From the perspective of further pas development, several points are central. First, the editorial states that because "family members often assume the burden of long term patient care," therefore, relatives can (and should) be educated to help monitor and control the use of alcohol and illicit drugs. This inadvertently supports the position that the adults are a "burden" on society with the "family" holding responsibility, and that monitoring of legally responsible adults with disabilities is an appropriate role for parents. Second, the editorial proposes the education by non-disabled professionals in one categorical area (brain injury) of self help groups (alcoholics). Third, on agency policies, more exploration is needed regarding the relationship between policies (e.g., what is written), actual practices (e.g., what staff do), and outcomes (i.e., what happens in the lives of people).

Contributions to Conceptual Model:

The editorial was selected partially to represent the fact that model development which starts from a categorical disability base (e.g., brain injury, mental health) has tended to result in model systems for persons with "other" or "dual" problems (e.g., alcohol or substance abuse)[10]. This contrasts with approaches based upon regular growth and development (e.g., of adolescents) and with systems organized around the secondary issue (e.g., substance abuse). Secondly, each of the points mentioned above are significant areas regarding pas, since two of the three contrast with independent living philosophy, although the authors intended to support the goal of independent living: and the third is essential if any agency delivery systems (including independent living centers) are utilized (See also, Shaw, McGillis & Dvorchik, 1994, on ADA).

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[9] *Not concept used by this researcher, yet common in this literature.*

[10] *See, also "dual disorders of mental illness and substance abuse" (e.g., Psychosocial Rehabilitation Journal, special issue, 1991)*

***Keywords:** model systems, brain injury, alcohol abuse, education, rehabilitation, assessment and treatment, prevention, independent living, (agency) policy, outcomes research, community adjustment, insurance, vocational rehabilitation*

***Citation:** Singer, G. & Nixon, C. (1990). "You can't imagine unless you've been there yourself": A report on parents of children with traumatic brain injury.[11] Eugene: Oregon Research Institute.*

Summary:

This qualitative research report discusses the needs and concerns of parents of children who have sustained traumatic brain injury. The article is based upon group discussions ("focus groups") and individual interviews with 29 parents on the east and west coasts whose children ranged in age from 4 to 40. The methodology included the analysis of recorded transcripts and field notes. Organized around the general course of life following the injury: the accident, the period of coma, of intensive rehabilitation, of reintegration into home and school, and of transition to adulthood, the authors conclude that current social institutions are only minimally aware of the social and emotional impacts upon the family.

Analysis:

The authors attempted to identify "the needs and concerns of of parents of children who have suffered from traumatic brain injury" and organized the findings according to how the parents presented their life histories. It is an excellent, readable account of perspectives which are important in moving toward community, personal and family support approaches.

Contributions to Conceptual Model:

The authors' focus was not on the perspectives of the children with brain injury. However, in relationship to PAS, the article identifies several areas that may also be considered important from the perspectives of the children:

- *Distinguish between adult and youth models, especially incorporating the age of the youth (e.g., young children and adolescents);*
- *Provide "simple and clear" information access;*
- *Frame decisionmaking from the person's perspective, not solely in parental and professional terms;*
- *Incorporate the themes of parental values such as uncertainty, hope, personhood, the value of personal caregiving and the emotional drama of "recovery of consciousness;"*

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[11] *Also, see direct accounts by parents, such as Injured mind, shattered dreams (1994) by Janet Miller Rife, and Betty Pieper's accounts of her parental experiences.*

- *Highlight the roles of community institutions (e.g., churches, youth groups and schools); and*
- *Incorporate the goal of independent living as the child becomes older.*

The article also describes five areas which are part of the development of any PAS model:

- ***paraprofessional roles**. (E.g, nurse relationship as an important one as compared to doctor);*
- ***behavioral issues**. Experiences of parents with the "behavior" problems of their children, and its effect on the family;*
- ***friendships**. The child's and their loss of friends, partially by time away from school;*
- ***parents' support needs**. Needs for social, respite and casemanagement, and financial support;*
- ***school programs**. Placement of children with brain injuries in school programs with children with learning disabilities and/or mental retardation;*

Keywords: traumatic brain injury, rehabilitation, families, community reintegration, transition; education, independent living

***Citation:** Virginia Department of Education. (1992). Guidelines for educational services for students with traumatic brain injury. Richmond, VA: RRTC on SSBI with Virginia Department of Education[12].*

Summary:

The guidelines, developed by a diverse team, provide an excellent tool for educators who are trying to overcome the barriers facing students with traumatic brain injury (tbi) in obtaining the education that they may need and want. Produced subsequent to the 1990 reauthorization of the Individuals with Disabilities Act (IDEA) which "included traumatic brain injury as a separate category,", the monograph offers diverse information: (a) distinctions betweeen tbi and other "categorical labels;" (b) common problems and "deficits" following tbi; (c) family, sibling, parent-educator, school-family partnerships and family community needs; (d) successful education programming (training, evaluation, planning, implementation and monitoring) within a "tbi team model" and a "continuum of educational placements"; and (e) appendices on the human brain, Section 504 and IDEA, sample functional and vocational assessments, and observable behaviors and potential strategies.

Analysis:

From the perspective of PAS development, the guidelines are an effort to have classroom educational practices become more flexible and respond to the educational needs of students

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[12] *See, also Lange, M., Lange, S., & Turnstal (1991). Needs of students with acquired brain injury in community college. Cognitive Rehabilitation, 22-24.*

(e.g., flexible scheduling, altered demands, integrated therapies) and their families. The observable behaviors and strategies focus on what teachers can do (e.g. use printed or pictorial schedules), and not on how teachers might assist students to incorporate these strategies (e.g., cuing) or to develop one's of their own. Services provided by teacher aides and assistants (roles which may overlap with personal assistants in schools) are not discussed with the roles of the interdisciplinary teams (school based, brain injury) and "casemanagers" (liaison, coordinator and monitor) highlighted.

Contributions to Conceptual Model:

The future roles of personal assistants (for children and youth with disabilities) in schools are dependent upon the framework used for integration or inclusion within the educational system or the position(s) taken on school reform. The monograph offers several immediate areas to address: better inclusion of students in their own lives and life planning; and use of student assistants with incorporation of "self-help" and "self-management" strategies. On the policy level, it raises the question of whether the availability of personal assistance (other than in its current senses of personal care or its incorporation within aide roles) can be accomplished without school reform.

Keywords: *education, (traumatic) brain injury, IDEA, school-family partnerships, parent-educator partnerships, interdisciplinary teams, individualized education plans*

Citation: *Whyte, J & Rosenthal, M. (1993) Rehabilitation of the patient with traumatic brain injury. In J. DeLisa (ed), **Rehabilitation Medicine: Principles and Practice**. Philadelphia: Lippincott. (pp. 825-853)*

Summary: *The article identifies and describes functional areas (e.g., impaired mobility, memory deficits), cognitive impairments (e.g., arousal and attention, learning and remembering), social and behavioral disabilities (e.g., reduced initiation, awareness, substance abuse), medical problems (e.g., seizures) and physical impairments (e.g., sensory deficits, nutrition) which may accompany brain injuries. It also delineates several areas of everyday task functions for people with brain injuries, including community mobility, self-care skills and educational, pre-vocational and vocational functions.*

Analysis:

The article provides an excellent introduction to the difficulties that people with traumatic brain injuries may face from a clinical and medical perspective (e.g., seizures, bowel and bladder problems, sensory deficits, nutrition, increased muscle tone and contractures), the ways in which these may affect the person and their family, and critical issues in the development of PAS models (e.g., legal competency and conservators, difficulty in acquiring new information by service users and their families, difficulty in learning alternate strategies in circumstances of severe brain injury), and the perceived difficulties by clinicians (also reported by parents) in the "management" of behavior.

Contribution to Conceptual Model:

The article provides a comparison base of professional rehabilitation services for people with brain injuries. This includes types of functional impairments related to everyday life which people may wish to have more control over through a personal assistance service system. Especially in the area of "cognitive" issues related to decisionmaking, the chapter identifies specific professional areas to address in the development of a self-directed and/or assisted, non-professional model(s) of PAS "for" people with brain injuries. Information access and legal access (based in this article upon capacity in contrast to other approaches) and protections of the individual's rights are important features of PAS. A reframing of the "behavior management" issues is essential, with ways of self-"managing" behavior (i.e., effectively retaining and developing in jobs, home, friendships, and chosen areas of life when the person or others experience problematic "behavior") (See movement toward behavioral supports).

Keywords: *brain injury, rehabilitation, cognition, management,*
community functioning

Citation: *Wright, B. (1993).* What legislators need to know about traumatic brain injury. *Denver, Co: National Conference on State Legislators.*

Summary:

Prepared for use by legislators and policymakers, this monograph presents an overview of traumatic brain injuries and its affect on people with brain injuries, their families, and society. Based in part upon site visits to brain injury programs in different states conducted by Bill Reynolds of the NYS Department of Health, this paper succinctly and persuasively presents data and summarizes information on: why legislators should be concerned (e.g., high cost to society of inappropriate care, growth of advocacy groups), the types of services people need (i.e., trauma system, housing, job training and placement, income supports, education, home and community-based support services, rehabilitation), the availability of federal assistance (e.g., health care, prevention), private insurance coverage (e.g., self-insurance, health maintenance organizations and preferred provider organizations, workers' compensation), state service delivery in New York, Missouri, Massachuseetts, Minnesota, "options to support services" (catastrophic riders, self-sufficiency trusts, state high risk pools), state financing (through Medicaid waivers, dedicated funding streams), prevention of head injuries (e.g., seat belt and child protection laws; penalties for drinking and driving), and innovations within states (central registry system, supported employment, comprehensive services).

Analysis:

As a well-written monograph, the paper highlights a variety of approaches in a wholistic context. Not designed to be presented from the points of view of youth, adults, and families with traumatic brain injuries, both the National Survivors' Council of the National Head Injury Foundation and independent living as a program model are included. The paper is one of the *few which present family support from a non-therapeutic family perspective, inclusive of family subsidies[13], family-centered services such as support workers, support groups, chore assistance, and in-home training to deal with crises and behaviors, and the provision of durable goods which may be related to medical condition or family need.*

However, it does not distinguish community housing from residential arrangements or employment from rehabilitation service models, describes "personal care" as a paid service (for "eating, bathing, personal hygiene, cognitive supervision, and activities of daily living"), and details specific program models at places like community colleges and residential sites, some of which use a personal assistance services (generally agency-based or user-directed within an agency) model (e.g., Accessible Space, Minnesota or Options in Community Living in Wisconsin). With a non-medical approach, it presents critical practice and policy information for people who are interested in community life and movement toward quality.

Contribution to Conceptual Model:

The article is a good primer for PAS model development, for example, in terms of the identification of state and local sites which incorporate personal assistance services. Although not described in the paper, a number of the financing models are and/or could be used for the provision of personal assistance services[14]. Each of the points in the analysis are relevant to pas development: agency-based and user-directed within agency-based models; family support and movements toward "non-therapeutic" supports; personal life outcomes based on the individual's values; efforts to distinguish between program models and employment, home and recreation. The paper also specifically introduces the concept of prevention (if PAS is perceived as a prevention model), and identifies entry points for PAS (now often structured either as embedded program services or less flexible model types) in environments such as schools.

Keywords: *(traumatic) brain injury, public policy, legislation, state program models, service innovations, health care, financing (insurance), community services, (vocational) rehabilitation, prevention, housing, employment, recreation, education*

Citation: *Christiansen, C., Schwartz, R. & Barnes, K. (1993). Self-Care: Evaluation and Management. In Joel D. Lisa (Ed), Rehabilitation Medicine: Principles and Practice. Philadelphia, PA: J. B. Lippincott Co. (178-200).*

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[13] Subsidies for individuals or voucher approaches are not described explicitly, or the use of subsidies for areas such as recreation or housing.

[14] Effective analyses of financing across disability groups and financing sources on the state levels related to pas have not occurred (See, World Institute on Disability case studies of six states, for one type of analyses, 1991).

Summary:

The chapter describes a framework for thinking about self-care including the importance of "activities of daily living" to the individual, family and society, the relationship between self-care and independent living, and the assessment and management of self-care skills. In particular, it reviews self-care scales and approaches ranging from "restorative training" to technological developments to the "use of personal care assistants" in "promoting independence in self-care." The authors hold that "part of the rehabilitation process for people who are going to require attendant care is that they learn to recruit, hire, supervise, and if necesary, terminate personal care attendants." The article describes both personal care and the instrumental activities of "food preparation, laundry, housekeeping, shopping, the ability to use the telephone, use of transportation, medication use, and financial management, child care, leisure and recreation.

Analysis:

The chapter presents a user-directed model of personal assistance services which is consistent with an independent living perspective. Providing a useful counterpoint to a broadened definition of personal assistance, it offers comparative information for an analysis of progressive professional "management" of self-care and strategies for moving toward personal decisionmaking processes by people with significant brain injuries. Because of the critical role of assessment in personal choice and control, the section describing the indices can also be valuable. The article provides information on "developmental or habilitation," "restorative," and "compensatory" training which will be essential for the analysis of the role, if any, of personal assistants in areas such as training (E.g., training by people with disabilities versus current approaches).

Contribution to Conceptual Model:

As part of a textbook in the field of Rehabilitation Medicine, the chapter introduces students to the critical concepts of self-care (inclusive of self-management) and personal assistance services. In terms of pas model development, it raises the issues of "habilitation" and its role with personal assistants, the distinctions between management by others and self-management, training (for example, by service users) and a user-directed model within the context of a clinical and/or rehabiitation setting.

Keywords: *self care, rehabilitation, rehabilitation medicine, personal assistance services, personal care, community re-entry, community services*

TOWARD PERSONAL ASSISTANCE SERVICES IN THE FIELD OF MENTAL RETARDATION AND PHYSICAL DISABILITIES

For adults with mental retardation and physical disabilties, supportive/ed living and supported parenting are approaches to assisting people to live in homes of their own choosing with support services (and assistive technology) they may need and want to do so (Racino, 1995; Johnson, 1985; Kennedy, 1993). New demonstrations of personal assistance services (PAS) have also been funded by the Administration on Developmental Disabilities (1994), and examples with adults with significant disabilities can be found in many states (Taylor, Bogdan & Racino, 1991).

This section is organized around:

- *two personal perspectives on personal assistance services with two others together with a parent pespective on supportive living);*
- *an article with People First perspectives on employment and one on coworkers and supported employment;*
- *a status essay on personal assistance services for people with mental disabilities prepared for the National Council on Disability;*
- *a monograph on personal assistance services prepared for the Georgia Developmental Disabilities Council;*
- *an article on pas for people with mental retardation prepared for the Pas International Symposium;*
- *a research article on lifestyle planning and a conceptual one on choicemaking;*
- *a leading provider text about a support organization, inclusive of personal assistance);*
- *two books on housing and support, inclusive of pas and supportive living), on organizations supporting people with severe disabilities;*
- *a book on the new support classification of the Association of Mental Retardation;*
- *a book on community integration (inclusive of recreation, employment, self advocacy, families, homes and guardianship);*
- *a qualitative research article on schools, and one on related services and instructional strategies;*
- *two family and in-home support research and policy articles, inclusive of pcas);*
- *an article on Medicaid and personal assistance services prepared by the National Association of State Directors[15], and a research study on insurance and pcas.*

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[15] *No articles or policy documents are included which compare personal assistance across the programs (inclusive of pas) in the field of mental retardation and personal assistance services in the programs developed initially for people with physical disabilities.*

***Citation:** Ludlum, C. Cathy's story: The power of a circle of support. In C. Ludlum, P. Beeman, & G. Durcharme, Dare to Dream: An analysis of the conditions leading to personal change for people with disabilities. Manchester, Ct: Communitas Publication.*

Summary:

In this essay, Cathy Ludlum describes her efforts after college to "move into my own place, where I would have both the freedom to run my own life, and the support I needed to be safe." After hearing a presentation by David Wetherow on a housing cooperative in Canada, three people from Connecticut (George Ducharme, Pat Beeman, Beth Mount) took her dreams seriously. Together with her "circle" and Sara Page, she began a project to bring accessibility to Connecticut co-ops.

Cathy Ludlum hired personal assistants ("seemed like an incredibly risky endeavor") with the backup of her circle. She found that her independence had increased, her fears were unneccessary, and her pcas (personal care assistants) reliable. She also joined a health care coalition, since her employment has always hinged on the issue of health insurance. She began a business as a communications consultant, "doing writing, editing, graphic design, speaking, and other tasks." At the time of the article, Cathy Ludlum was not yet living in the cooperative (which has since opened).

Analysis:

As part of the Communitas publication series, Cathy Ludlum's personal story was shared as illustrative of the conditions of positive change: the desire for change, personal vision, support circle, connection to a wider network, community builders, personal capacities, and (personal) champions. PAS is conceptualized within the larger framework of "circles of support," as a form of paid assistance, potentially through health insurance.

Contribution to Conceptual Model:

The major contribution, now being popularized in the field of developmental disabilities, is the framework of "circles of support," which varies in its conceptualization from other ways of thinking about paid and unpaid assistance; however, differing somewhat from IL on relationships. A user-directed model of PAS for persons with physical disabilities, paid by health insurance, was endorsed; contributions in valued connections outside the field of disability.

***Keywords:** support, personal assistance, community, organizations, support circles co-operatives, business, health insurance*

Citation: Johnson, T. Z. (1985). Services to people with physical disabilities. In T. Z. Johnson, Belonging to the community[16]. Madison, WI: Options in Community Living with the Wisconsin Developmental Disabilities Planning Council.

Summary:

One of the best service provider manuals describing an organization which has become recognized as a leader in supporting adults with developmental disabilities to live in their own places. A summary of the full manual is included in an earlier PAS bibliography from the ILRU in Texas (Nosek et al, 1990), since it is one of the first publications in the field of developmental disabilities to explicitly discuss personal attendants.

A specific section also describes the organization's efforts to expand their services to adults with physical disabilities through a state "capacity building grant." These learnings included increased time and changed roles of casemanagers, strengthening of paraprofessional-family team model[17], expansion of attendant services beyond personal care and housekeeping, strategies on improving attendant care (e.g., Options supplement to attendant wages), more systematic recruitment and screening, "creative scheduling" (e.g., dividing position into two part time ones), and clarifying "supervision" (person as the legal employer, with clarification of job descriptions, functional responsibilities, agreement between the employer and attendant, apartment meetings - especially if a group of attendants, evaluation of attendants). Options' staff also took a "stronger" control rather than advisory or consultant role when the person "seemed unable to direct their own care."

Analysis:

Other areas of the manual remain as stronger contributions to PAS development; for example, the discussion on the dilemma of client autonomy (e.g., the advantages of a consumer-directed model, controlling risks through relationships and quality of life standards), and the comparisons between the assumptions underlying traditional residential services and Options' approaches. However, the capacity-building grant appears to have led to greater professionalization with stronger control on the part of the agency workers, entry to services by new people, and better working conditions for workers (which may not be related to the specific categorical group).

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[16] *More updated materials also exist on this organization, such as The Soul of Our Work, which reflect stories of people's own experiences (e.g., workers). For a research case study of the community housing association, see Racino (1993), and for Wisconsin community living, See Taylor, Bogdan & Racino, 1991.*

[17] *The team model has changed on numerous occassions since 1985. In reviewing provider texts and organizational studies, it is important to note that the written information reflects the status of the place at that point in time.*

Contribution to Conceptual Model:

Options' approach has been important in moving away from more standardized models of residential services to one's based upon quality of life standards, inclusive of beliefs in consumer-direction of services, participation in community life, zero exclusion, and the separation of housing from flexible supports. The approach represents one of the better approaches to housing and supports in the field of developmental disabilities,[18] *with good coordination with housing association development.*

Keywords: *attendant services; supportive living; casemanagement; innovations in organizations; physical disabilities; developmental disabilities; human service organizations; personal autonomy; quality standards; relationships*

**Citation: Nosek, M. (1990). Personal assistance for persons with mental disability*[19]*. Houston, Texas: Baylor College of Medicine (prepared for the National Council on Disability).*

Summary:

This is a brief 12 page paper describing personal assistance in the field of mental retardation and mental illness. In mental retardation, the paper highlights changes in ideology, funding, formal programs, and informal support, while in mental illness, the paper highlights supported housing, case management, and informal supports.

In the field of mental retardation, the paper cites the concept of the "nonrestrictive environment" which contrasts with the principle of the least restrictive environment (LRE) as the basis for service design, excerpts one principle on community living for adults from the Center on Human Policy's, Syracuse University, Policy Institute; highlights Braddock's (of the University of Illinois-Chicago) mental retardation "spending" study, the use of the "Medicaid waiver" and arguments regarding the relevance and validity of the data; a growing body of literature on transition from "traditional models of residential services;" the role of the family (partially as surrogates); the interrelationships between formal and informal supports, including "circles of support," and the problems people with disabilities face in obtaining support services (e.g., lack of information).

In mental illness, the author highlights the "large, well funded service structure," supported housing (which "combines housing with professional case management, support services and facilitated peer interaction"); case management as an "important part of many different community-based mental health services," including those funded by "Medicaid;" and informal supports in the context of the "ex-patient movement," psychosocial rehabilitation

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[18] *A comparison of this approach with personal assistance services (PAS) and supportive/ed living approaches are described elsewhere.*

process, linking programs which match the "elderly" with "friendly visitors" and people with mental illness with "nondisabled volunteers," and individuals living on their own.

Analysis:

The paper is important because it begins to document a starting base for further development in PAS in "mental disabilities," which had not received as high a priority focus in independent living (IL). The paper's orientation is primarily on "community living" (in contrast, for example, to employment, recreation, political life) for people with "mental retardation" and "mental illness" as described in an emerging body of parent and professional literature. This paper does not attempt to integrate, compare or contrast these perspectives with the independent living movement, with national goals, or with any type of cross-disability analyses.

Contribution to Conceptual Model:

The author indicates several key areas for conceptual model development: (1) the nebulous nature of tasks such as "helping with making decisions, organizing daily activities, or offering ongoing emotional support"; (2) the nature of large, separate structures or service systems in these two fields; (3) the "progressive" professional base for more consumer-directed approaches to housing and support services; (4) the role of non-professional support networks in "helping people" maintain their "independence and productivity in the community"; (5) the roles of companion, volunteer and case management models[20]*; (6) the critical role of families and their interrelationships with service systems*[21]*; and (7) need for funding reform.*

***Keywords:** personal assistance services; mental disabilities; mental illness; mental retardation; Medicaid; supported housing; informal supports; community services; consumer movement*

***Citation:** O'Brien, C. (1992). __To boldly go: Individualized supports for Georgians with severe disabilities__. Georgia: Georgia Developmental Disabilities Council.*

Summary:

The monograph is an excellent contribution to an understanding within the field of developmental disabilities of personal assistance services, and the conceptualization within that field. It defines personal assistance within the context of individualized support (i.e., adaptive technologies, transportation, PAS, housing, good health care, and planning and problem solving) and the commitments, associations, assistance and political action agendas which promote the well-being of people with disabilities.

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[20] *Casemanagement and service coordination are presented as accepted professional forms.*

[21] *Families are discussed partially in the context of speaking for people with mental retardation and developmental disabilities.*

The definition of PAS ("one or more people assisting another person with tasks that person would do if not disabled") (See, for example, Litvak et al, 1991) is consistent with that of the World Institute on Disability and in this description includes most areas of assistance other than personal and emotional support, and explicit assistance in leisure, spriritual, political and community life. A 33 item checklist which includes direct receipt of PAS or vouchers by assistants to hire and supervise self-employed providers, encouragement of natural supports, wage and benefits of attendants, and income criteria guidelines. The Appendices also describe financing in Georgia, most of which is applicable in other states.

Analysis:

The monograph describes PAS through an integration of two frameworks, the independent living movement's user-directed approaches to PAS and the mental retardation/developmental disabilities' approaches to "individualized support" and community life (e.g., relational, associational). Prepared for the state of Georgia, this resource contributes to the practical translation of PAS to people with "cognitive" disabilities (primarily mental retardation and developmental disabilities) in ways that are usable across different states. In addition to the integration of the frameworks, the author also identifies another source of potential funding.

Contribution to Conceptual Model:

The monograph is one of the best "practice" pieces available for service providers regarding the development of personal assistance services (PAS) "for" people with mental retardation and developmental disabilities. The framework integrates the approaches used in developmental disabilities policy and financing, including in the federal Community Supported Living Arrangements (CSLA), state supported(ive) living, and personal assistance.

Keywords: *individualized supports, personal assistance, severe disabilities, community living, financing, independent living, community supports, service coordination*

Citation: *Smith, G. (1994). Medicaid PCA services in Massachusetts: Issues and options[22]. Boston, MA: (Prepared for the Massachusetts Developmental Disabilities Council and Human Service Research Institute by the National Association of State Developmental Disabilities Directors).*

Summary:

In the context of the "debate"(s) around PAS for, by and with adults, children and youth with (cognitive) disabilities, this report examines Medicaid-funded personal care

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[22] *See series of the National Association of Developmental Disabilities Directors, including reports on Community Supported Living Arrangements, the Home and Community-based (HCB) Medicaid waiver, Supported Living, and Managed Care.*

assistance/attendant services (pca), conducted as a followup to a 1992 survey by NADDS, in order to provide information to the Massachusetts Developmental Disabilities Council. The report summarizes: federal policy on personal care in the 80s and 90s; nationwide trends in personal care, with examples from Michigan, Wisconsin, Minnesota, New Hampshire and Maine; pca coverage, denials, and policies in MA; and recommended policy options (e.g., "permit furnishing personal care in the family home;" "permit consumers to receive pca services" minimally when also receiving other living arrangements, and on a "customer-based" approach, not on the basis of "disability labels;" and authorizing pca through existing casemanagement and "attendants to accompany individuals to activities other than medical appointments."

Analysis:

The author includes a number of important areas to future pas model development in terms of service system arrangements and disability policy: (1) create an entitlement for pca services; (2) current feature (relatively unique among the states) that pca take direction from consumer or surrogate[23]and that the consumer hire the pca (though "affiliated with pca agencies"); (3) comply with federal law to assure that pas is not denied on the basis of categorical disability (e.g., mental retardation versus mental illness); (4) look at all policies that affect all populations who need long term support; (5) pca services and its use with community and person-centered systems of support, including with other sources of federal funding; (6) personal care as "useful in meeting the needs of families" in contrast to approaches strengthening the direction of children, youth and adults with disabilities of their own lives; (7) "no state which authorizes personal care services as a means of giving the family respite from caregiving per se" apart from the home and community-based (HCB) waiver program; (8) EPSDT as a "clumsy vehicle for accessing any type of long-term support services," and (9) the coordination of pcas (generally paid services) with natural supports (friends, family).

Contribution to Conceptual Model:

Each of the specific areas noted above are questions of public policy in the development of user-directed models of PAS. In particular, conceptual and philosophical clarification would be useful in relationship to pas and family support with children and adults living at home (thei report appears to reverse the IL model); between models which require "affiliation" with agencies (including independent living centers) and those which are direct models of control; and with the relationship among person-centered and community-centered, pca services, long term support on a cross population basis, and natural supports.

Keywords: *personal care assistance, attendant services, developmental disabilities; Medicaid; cognitive impairments; public policy; federal financing; health care*

Citation: *Taylor, S., Bogdan, R., & Racino, J. (1991). Life in the community: Case studies of organizations supporting people with disabilities.*[28] *Baltimore, MD: Paul H. Brookes.*

Summary:

As part of the first national study of its kind, the book presents a series of qualitative research case studies on organizations offering family support (for "families and their children"), on organizations supporting adults in "housing" and "homes", and on organizations which are changing the nature of their relationship with community and society. The introduction briefly discusses five organizational types (benevolent, professional, intentional, social change agent, and person-famly centered), and the conclusion describes the characteristics of "good" organizations.

The family support studies examine supports in three states, with two perspectives (family, regional/state) in Michigan, county-based services in Wisconsin, and family supports inclusive of children with health needs in Maryland. Of the organizations in the housing and support area, one is group home based, another is semi-independent living with parent services, one represents an agency in an initiated process of change with a second chapter on the same agency, and two chapters based on moving toward "individualized" services and supports.

The final sets of chapters were selected for inclusion in this book to highlight particular areas of concern: urban, inner city issues; gender issues in mothers caring for children; foster homes; intentional communities; advocacy organizations; and a (support) organization involved in changing the nature of its relationship with the community.

Analysis:

An analysis of the case studies as research data are included in another article (Racino, 1991). The case studies are important in describing "good" organizations in the field of mental retardation and developmental disabilities, and represent part of the data base for frameworks on family support, housing and support, and community support as presented by the Center on Human Policy. "Attendant care" specifically is either identified as a category of "family support services" (e.g., in Wisconsin), or as "personal care" or "attendants" for people (primarily with physical disabilities) who live in "a client's home" (e.g., Options in Community Living).

Contribution to Conceptual Model:

In the area of families, the primary contribution was the finding that children with severe

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[28] *For series of case studies upon which this book is based, see Community Integration Reports, Center on Human Policy, Syracuse University; for a journal article describing the national study results, see Racino (1991) on organizations in community living; for study on adults with disabilities, see Racino, (in press).*

disabilities, inclusive of medical needs are living with families (with the availability of support services). Secondly, that adults with significant disabilities can be supported to live in regular homes in the community with the availability of up to 24 hour flexible and individualized support services (inclusive of a new identification of an adult service type which varied in almost all major aspects from traditional and common residential service arrangements in the U.S.). The study also offerred information on specific aspects of design of "support" inclusive of "services."

Keywords: *human service organizations, housing, (individualized) supports, family supports, community living, developmental disabilities, community, parents with disabilities, intentional communities*

Citation: *Racino, J., Walker, P., O'Connor, S. & Taylor, S. (1993).* ***Housing, support and community: Choices and strategies for adults with disabilities****. Baltimore, MD: Paul H. Brookes.*

Summary:

The book has two primary frameworks for understanding community living for adults with disabilities who have often been excluded from regular lives in the community. The first is a housing and support approach, which is particularly useful in state service system redesign, and the comparison among the rehabilitation, independent living, and emerging support and empowerment paradigms (See, also, Racino, 1992). Funded by the National Institute on Disability Research and Rehabilitation (NIDRR), the book is based on qualitative research, state technical assistance (inclusive of evaluations), training and literature reviews conducted between 1985 and 1991 primarily in the United States on community living for adults with the most severe disabilities, and their families.

Based upon the assumption that all adults can live in their "own homes," personal assistance services is reflected in several ways throughout the book. These include as a central concept in a policy statement in support of adults, as a service and priority in one organizational research case study of an independent living (IL) center; as user-directed personal assistance services in the chapters on support and residential "support organizations;" as part of Medicaid home and community-based waiver financing; in two essays written by leaders with disabilities who use PAS and an essay by a personal assistant from Canada, in the foreword co-written by a leader in independent living (IL) and another from mental retardation/developmental disabilities, and in the references and bibliography which accompany the book.

Analysis:

All the work upon which the book is based is original to the United States in the area of community living for adults with significant disabilities. The work reflects significant conceptual and practical developments, with short and long-term implications for adults with disabilities and their families, local and regional agencies, state service systems, and federal and state policy. The book primarily reflects agency-based designs for support and assistance, and user-informed *types of assistance; however, the book has excellent examples of housing associations and person-centered approaches to support and change. The book does not explicitly address transition from youth to adulthood; nor does it integrate the work on disability with housing and support for elders and other disability groups; or with broad public policy, or community associations, local communities or neighborhoods.*

Contribution to Conceptual Model:

The book provides an update on the status of agency-based support services for adults with developmental disabilities, and sets a framework for further research, training and technical assistance to move toward more user-directed and responsive support, and if desired, services and systems within the United States.

***Keywords:** housing, supports, personal assistance, community living,*
community organizations, independent living, rehabilitation

***Citation:** Racino, J. (1992). **Thoughts and reflections on personal assistance services: Issues of concern to people with mental retardation**[25]. Syracuse, NY: Syracuse University.*

Summary:

This essay appears to be the first in the USA to discuss or analyze personal assistance services for people with mental retardation outside of the federal, state and local program descriptions. The paper addresses aspects of PAS of particular relevance to people with mental retardation: user definition and determination of services, the person with a disability as the expert, personal determination and family empowerment, and the relationship between paid and informal services.

The author also lists seven common flaws of existing generic PAS services, and briefly highlights issues of decisionmaking support, entitlement or cash assistance, fight over who knows what is best for people with mental retardation, integration of people with mental retardation into the existing inadequate pas system, and rights versus mutuality. It ends with recommendations with how we can work together to organize around common issues and seek opportunities for exchange.

Analysis:

Prepared for the International Personal Assistance Symposium, the article drew on informal and formal discussions on support services in 25 states in the U.S., and was the first

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[25] Also, see community living journal articles, Racino & Heumann (1992) on Independent living and community life: Building coalitions with elders with disabilities; Racino (1995) on Personal assistance and personal support services (cross-disability).

effort to translate these issues within the framework of personal assistance. Three areas are identified for future research, including the potentially controversial area of adults with mental retardation who may wish to be more independent, but do not have access to the kinds of "supports" that their parents do in order to move away from the family home, if they so desire.

Focused primarily on adults, the article raises different concerns than those of children, youth and families in relationship to PAS. Like the work on community integration of this period, it tends to reflect perspectives from people who are Caucasian and middle class, and who typically do not live in inner city areas. The framework for analysis is community integration, as opposed to independent living, and also includes comparisons between two separate systems, one primarily designed for people with physical disabilities and the other for people with mental retardation.

Contribution to Conceptual Model:

Each of the identified issues in the article are based upon an analysis of areas for future support development. As an example, conflicting positions on the relationship between paid services and the "use of" informal supports (e.g., family, friends, neighbors) have direct implications for service design (e.g., eligibility for services; financing of services; training of assistants).

Keywords: *personal assistance services, self determination, family empowerment, mental retardation, developmental disabilities, decisionmaking, community services, independent living, self advocacy*

Citation: *Guess, D., Benson, H. & Siegel-Causey, E. (1985). Concepts and issues related to choice-making and autonomy among persons with severe disabilities in classroom settings.* ***Journal of the Association of Persons with Severe Handicaps****, Vol. 10(2), 79-86.*

Summary:

The article was written to conceptualize an approach and to "direct attention to" choice-making "as an important component of future practices" in the education and treatment of "persons with severe handicaps." It was intended to counteract the beliefs that persons with severe handicaps are not capable of making choices in their own best interest, and to mitigate against the use of "worst scenario" when people take risks.

The author supported a continuum of abilities in understanding and expressing preferences and the decisionmaking processes required for choice-making, and the categorization of these levels for purposes of educational interventions. The authors present their framework through a discussion of preferences, responsiveness to preferences (e.g., nonverbal behaviors in the context of communicative intent), choice as a decisionmaking process, and choice as an expression of autonomy and dignity. In regard to the latter, the authors primarily describe the relevance of overcoming "learned helplessness" (Seligman, 1975), illustrating also how communication of *choices can be a matter of "survival" for people who are "dependent upon others" to move, dress and communicate. The authors contrast this framework with approaches with people with severe handicaps which result in "more control for the caregivers and less for the person being cared for." They also refer to studies in the 70s which examined "maximizing contingent experiences" to build independence, choice and control into daily activities.*

The authors identified three independent variables to be explored in future outcomes research: assessments of the extent to which choices and decisionmaking are provided across and within environments; nature and conceptual bases of training programs and curricula; and personal attitudes towards choicemaking (and autonomy) by those caregivers and instructors who provide the training. The article cites the absence of extensive research data on the development of decisionmaking skills, the ongoing work conducted at the University of Kansas (e.g., parents of adolescent students), and argues for qualitative research techniques as an appropriate method for investigating choice and decisionmaking opportunities.

Analysis:

The article was significant in the educational context of students with severe handicaps in identifying and highlighting a critical, yet neglected area, which has since gained greater popularity. Significantly, the authors note that the article "is likely to be perceived by some persons as threatening to current state-of-the-art technology," with choices and decisionmaking major concerns in employment, family support, recreation, health care, and community living.

Contribution to Conceptual Model:

The article was selected to represent the emerging attention within the field of developmental disabilities to the area of choices and decisionmaking as broader than the preceeding work (which does not translate well to community life). For purposes of pas model development, two major approaches can be taken from the article: a reform agenda based upon a new way of approaching how choices and decisionmaking are conceptualized for people with severe handicaps; and qualitative research on areas significant to pas development, such as training, assessments and choicemaking across diverse environments.

***Keywords:** severe disabilities, education, personal autonomy, choice, decisionmaking, outcome research*

***Citation:** Rusch, F., Hughes, C., Johnson, J., & Minch, K. (1991). Descriptive analysis of interactions between co-workers and supported employees[26]. **Mental Retardation**, 29(4), 207-*

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[26] *Articles on supported employment and/or transition are popular in the mental retardation literature, including articles in American Journal of Mental Retardation: Chadsey-Rusch (1992), Johnson & Rusch (1992), Trach & Rusch (1989); JASH: Rhodes et al (1991), Wehman & Kregel (1985), Noble & Conley (1987), Rhodes, Ransey & Hill (1987), Hill et al (1987), West & Pc[illegible]t*

212.

Summary:

The article describes co-worker roles based upon a sample of 341 supported employees "served by community rehabilitation facilities implementing supported employment programs throughout the state of Illinois." The purpose of the study was to "extend the work behavior literature" and to better understand the roles which may be emerging between supported employees and employees without disabilities (i.e., non-disabled coworkers). The authors note that six types were reported at the time the study was submitted: advocating, associating, befriending, collecting data, evaluating, and training (e.g., Nisbet & Hagner, 1988). Data collection for the descriptive study occurred in 1988 with survey forms completed by the employment specialist "who was primarily responsible for providing postplacement, long term follow-up." The study found that all roles were reported for all levels of mental retardation (mild, moderate and severe/profound), with "the greatest percentage (87%)" of people having coworkers who assumed roles as associates (i.e., "interacting socially with employees at workplace."); the least reported role was as a friend" (23%). Over half of the supported employees were trained by their co-workers; with a "large percentage evaluated by their coworkers" with few interactions reported outside the workplace. "Results suggest that co-worker interactions may reflect support that is natural to the workplace."

Analysis:

The article was selected as an example of the emerging literature on supported employment, and studies reflecting the "social acceptance" and role of "natural supports" within the workplace (see, for example, Hagner & DiLileo, 1993). The context for understanding, implementing, and researching any PAS related to employment, requires both role issues related to the employment specialist (job coach) and co-workers, supervisors or others within the workplace who may already be (naturally) playing those roles.

The article suggests that typical relationships may already be occurring, while other human service interactions (e.g., collecting data) may not have permeated these workplaces. The large percentage of training by coworkers is significant, if employment training is considered to be an appropriate role for a personal assistant. The study itself predates research on the mutuality of interactions in the workplace, on analyses related to the Americans with Disabilities Act, on regular personnel and employer mechanisms (e.g., employee assistance programs), on work culture and its relationship to employee (paid or unpaid) assistance, on "natural" and "community" supports and support frameworks in employment, and on the place of employee choice within the workplace.

(1992), Everson (1991); and Mental Retardation: Shafer, Banks & Kregel (1991), McCaughrin et al (1993), Levy, Jessop, Rimmerman & Levy (1993), Parmenter (1993), Wilson, O'Reilley & Rusch (1991) and Goldberg, et al (1990), with this trend continuing in 1995 and 1996.

Contribution to Conceptual Model:

None of the twenty-nine (29) employment articles in these three journals reviewed directly discussed personal assistance services (PAS) (in contrast, see, Journal of Vocational Rehabilitation, 1995), including with people who also have physical disabilities, severe handicaps or severe/profound mental retardation. Some of the functions of personal assistants are already incorporated within the "supported employment" "models," which is one of the reasons that the role analyses (e.g., job coaches) in the context of reasonable accommodations by the employers remain important.

Also, the conceptualization of "individualized and flexible supports" (e.g., Taylor & Racino, 1993) as it applies to community living has been interpreted very differently in the employment, and has significant implications on "choice" and "decisionmaking" (which are not reflected in the choice approaches to employment). Finally, legislation such as the ADA, which could be a precursor to PAS in the workplace, assumes a different perspective (with different implications for employers and businesses) than that of the movement in mental retardation toward "natural supports" or toward more employee and family responsive ("accepting") workplaces in society.

***Keywords:** co-workers, supported employment, "behavior" supports, rehabilitation, employment, community instruction, social acceptance, "natural" supports, employment, reasonable accommodations, Americans with Disabilities Act*

***Citation:** Ferguson, D., Meyer, G., Jeanchild, L., Juniper, L., & Zingo, J. (1992). Figuring out what to do with grownups: How teachers make inclusion "work" for students with disabilities[27]. JASH, Vol. 17(4), 218-226.*

Summary:

This article describes details of inclusion of students with severe disabilities using an extensive example of one high school drama class. Based upon research conducted in eight schools by a team of four researchers, the article describes three inclusion outcomes for both disabled and non-disabled students (curriculum infusion, social inclusion, and learning inclusion). It then describes how the drama teacher and the special education teacher provided teaching support, prosthetic support, and interpretive support to one disabled student by developing both collaborative and consultative relationships with each other.

Analysis:

Selected as an example of qualitative research within schools, the article contributes to

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[27] *Also, see qualitative research articles in JASH on school inclusion and on friendships/relationships.*

an understanding of school environments, the nature of the interactions within those environments, the nature of the transactions, and the nature of the outcomes in lives of students. The article is significant in its reconceptualization of (educational) support and its contribution to the reframing of how inclusion "works."

The authors analyzed their data to identify incidents and events "that revealed various structural, logistical, curricular, and pedagogical dimensions" that seemed to create a kind of invisible "bubble" around the students with disabilities; developed concepts and categories related to role conflicts, role management and support; and informed the emerging research theme of "effective inclusion depends on figuring out what to do with the grownups."

Contribution to Conceptual Model:

For the purposes of PAS development (services level), the article particularly contributes to (1) the crucial need to examine the conceptualization of the role of the "inclusion facilitator" (as adaptor and broker); (2) the reinterpretation of (educational) supports (teaching, prosthetic and interpretive) which reflects a reasonable framework within classes to conceptualize PAS; (3) the roles of one-to-one aides within classrooms (e.g., "support" person as a bubble of isolation); (4) students with disabilities as teachers and the development of adolescent identities and relationships; and (5) the meaning of independent living in the context of a school inclusion and/or a school reform framework. The article also has other implications for agency-based service models, for example, pointing out the need for research in other sectors such as community life on how adults work with each other, when multiple adults ("grownups") are involved.

Keywords: *(supported) education, inclusion, qualitative research, adults (teachers), collaboration, developmental disabilities, integration, peer relationships, facilitation, (educational) support*

Citation: *Malette, P., Mirenda, P., Kandborg, T., Jones, P., Bunz, T., & Rogow, S. (1992). Application of a lifestyle development process for persons with severe intellectual disabilities: A case study report[28]. JASH, Vol. 17(3), 179-191.*

Summary:

The report "summarizes the results of four data-based case studies (two adults and two children) that examined the efficacy of the lifestyle development process (LDP) for persons with severe disabilities." The development processes also incorporate "best practices" in the fields of

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[28] *Also see, personal futures planning, O'Brien, 1987; MAPS, Vandercook & York, 1989; Mount et al, 1991, Communitas series; Smull & Harrison, 1992 on behavioral supports; and another on lifestyle planning and behavioral supports (Horner, Dunlap, Koegel, Carr, Sailor, Anderson, Albin, & O'Neill, 1990).*

behavioral[29], communication and instructional programming, and "outcomes measures to evaluate changes in the individual's social and activity patterns and to evaluate intervention effectiveness."

Consultant services were provided by an adult team (speech language pathologist, 3 behavior consultants, and instructional consultant) and a childrens' team (2 education/behavior consultants) with a goal not to supplant traditional service delivery or educational staff roles (Janney & Meyer, 1990). Data collection consisted of written inventories, field observations, interviews with families and service providers, record reviews and videotape analyses. The five step process of lifestyle development included: vision planning, assessing and remediating barriers to participation, assembling meaningful routines and schedules, developing specific intervention strategies, and evaluating effectiveness and developing a monitoring system.

The authors report that based upon the major interventions (e.g., curricular adaptations, change in service provider, circle of friends "intervention," task analyses), all four individuals engaged in a greater number of preferred, integrated activities during the mid and post-tests than at baseline; their social networks and program quality scores" improved; and reported "behavioral problems"..."were substantially reduced post-test for all individuals." Measures of intervention effectiveness used in the study were the resident lifestyle inventory, social network analysis, and program quality indicators.

Discussion of the implications of the findings centered upon changes in life outcomes (e.g., where people lived) and the need for more attention to social life "as a component of program planning," and the relationship between "best practices" and "best" program plans" in the context of a LRE program placement, continuum-based model of service design. On the future research, the authors wish to pursue instrumentation standardization, "assessment of functional relationships between multi-element support models and outcomes" and strategies for extending LDP to restrictive, segregated settings (e.g., sheltered workshops, day activity centers).

Analysis:

In the field of "cognitive disabilities," forms of person-centered and/or lifestyle planning have increasingly been used in schools and community living (see O'Brien & Lyle, 1987; Mount & Zwernik, 1988, and Vandercook, York & Forest, 1989). The authors hold that there has been "almost no empirical data" to document the outcomes and effectiveness of these approaches. This research study, however, is not based upon a study of any of these three approaches (i.e., the authors studied another process of planning). Instead the study reflects the evaluation of a lifestyle model based upon specialized intervention consultative team (i.e., "a social/political consultation") within the context of professional functions and systems designs.

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[29] *Behavioral supports or behavior management articles were a primary area of focus in the journals reviewed with over 18 articles appearing in JASH, AJMR, Childrens' Health Care, and Mental Retardation.*

The case studies were of people with significant disabilities (e.g., Laura used bliss symbols, written words, gestures and vocalizations for communication, engaged in "ritualistic behaviors" for hours at a time, and used medications such as thorazine[30]) and the life outcomes would be interpreted as significant. However, the data collection does not appear to have involved efforts to solicit information directly from the person instead focusing on direct observation of or data about the person.

Contribution to Conceptual Model:

One of the primary contributions of the article is that the authors make a persuasive case for the need to document the outcomes and effectiveness of new approaches; however, in doing so, outcomes and effectiveness research based upon existing methodologies may be inadequate to move toward the next development stages. The approaches to lifestyle planning have direct implications for PAS development within the fields of "cognitive disabilities" which, within the context of this article, would be considered as a service intervention.

***Keywords:** behavior management, communication training, community integration, friendship, individualized instruction, lifestyle planning, quality of life, participation, severe (intellectual) disabilities; education and training, social networks, functional skills*

***Citation:** Rainforth, B.& York, J. (1987). Integrating related services in community instruction[31]. __JASH__, Vol. 12(3), 190-198.*

Summary:

The article describes community-based instruction and transdisciplinary teamwork for educational services for students with severe handicaps. The discussion is framed within the use of an "ecological inventory" defined here as an "alternative assessment and curriculum model" (Brown et al, 1979) which is "community-referenced," and within the context of questions regarding the changing roles of related service personnel (e.g., physical, occupational and speech/language therapists). The article illustrates "how educational teams can expand current

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[30] Descriptions based upon deficits appear throughout this review, and are troublesome from the perspective of people who want to be viewed for their contributions and their strengths, and from the perspectives of people who view their disabilities as part of who they are.

[31] Only one article in JASH contains explicit reference to personal care. Also, see JASH articles on school programming for students with multiple (or "profound") handicaps; e.g., Campbell (1987); Downing (1988); Green et al (1986); Izen & Brown (1991); Mulligan et al (1988); Guy, Guess and Mulligan Ault (1993); and a review of self-management for individuals with severe handicaps (1985), and self-management study (1989).

practices to integrate related services (e.g., behavior management) into community-based instruction" through the use of individual examples, task sequences and objectives for the individuals for the library and MacDonald's, guidelines for integrated related services, and scheduling designs for staff and teams.

Analysis:

The article was specifically included because of its emphasis on community instruction, disciplinary teamwork, and the close parallel between how educational professionals think about non-core services personnel and the traditional, perceived functions of personal care assistants (when and if these functions are separated from the core "academic" program). As the counterpoint to "deficit-based" assessments and instructions, the article also significantly brings in the community-referenced curriculum (See, Syracuse University Curricula published by Paul H. Brookes), across school, work and community environments, which forms the basis for the education and preparation of youth with severe handicaps for adult life. While the article is dated in some ways (e.g., personal team approaches as an alternative; behavioral supports; and spontaneity in community life), the basic issues with community instruction and teamwork remain fundamentally the same.

Contribution to Conceptual Models:

For PAS development, in the field of education, it is essential to take into account the range of educational environments for students with severe handicaps. Unless kept to its original narrow definition, PAS actually would require yet another reframing of (paid) roles; with sufficient forethought and planning, PAS could be used as a tool to direct attention toward basic issues such as the school's role in promoting autonomy, decisionmaking and preparation for adult life in its youth (See, Youth development approaches to institutional change, Jackson et al, 1993).

***Keywords:** (community) instruction, education, teams, severe handicaps, community environments*

***Citation:** People First of Washington. (1986). Introducing: What we want from employment programs[32]. Tacoma, WA: Author.*

Summary:

The paper is one of a series of materials from People First of Washington which tries to present what it is "self advocates" want, in this case, from employment programs. Based on two

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[32] One of an emerging literature in self advocacy (for growth in US, see Hayden et al, 1995); also see, national self advocacy proceedings, annotated listings of self advocacy materials from the national arc and Center on Human Policy, Syracuse University, and recent research studies on self advocacy (E.g., Racino, 1993 on Self Advocacy in New Hampshire).

seminars conducted by John O'Brien and Connie Lyle of 100 self-advocates attending the International People First Leadership Conference, the paper illustrates through pictures and words, responses to five areas: "things that hurt", "things that help," "common experiences", "why" people have the experiences they do; and "ways to make employment better."

For example, ('Help') "by helping us to be part of a support group like People First; by teaching us to understand our wages and deductions so that we can understand the whole picture"; ('Hurt') "by not paying us enough money to live on...pay rent, buy food, and pay bills; by not giving us sick leave, vacations, or medical benefits given to 'staff' employees"; ('Common experiences') "staff do not listen to our ideas because they don't think we think; lots of people treat us like children and do not listen to what we have to say;" ('Why') "people see and think about my difference"; and ('What we want') "job programs," "respect through a decent wage," and "a chance to meet and know a variety of people."

Analysis:

The People First of Washington summary documents are important in developing a written avenue for people who are "self-advocates" to begin to create materials that represent their points of view on critical issues in their lives (e.g., employment). However, as early papers, they appear to reflect a combination of the views of the group of self-advocates, the facilitators and/or the recorders with a greater emphasis on job programs rather than jobs. The materials predate the growing formal organization of the national self advocacy movement (and the formal reports of these conferences), and efforts to formalize self-advocacy involvement within the state arenas.

Contribution to Conceptual Models:

It is very difficult to identify papers which clearly speak to what people, whether adults, adolescents or children who are "self advocates", want in their lives. No reference (other than one group name) is made to categorical disability groups like mental retardation, a term many self-advocates dislike. The paper does not explicitly discuss PAS, with the closest service parallel being job programs which can help people be more valued, obtain decent wages and benefits, and be listened to. It is most useful in pointing out the need to distinguish between the views of self-advocates, what professionals are trying to achieve and the ways which this may occur, all issues in PAS development. The pictures and the words reflect different questions and responses; however, with the major themes still valid today.

Keywords: self-advocacy; employment; Americans with Disabilities Act; self-help movement; job programs; People First

Citation: AAMR. (1992). Mental retardation: Definition, classification and systems of support. Washington, DC: American Association of Mental Retardation.

Summary:

The book describes the revisions in the AAMR definition of mental retardation to a multidimensional approach which specifies "adaptive skill" areas (and delineates how these skills should be documented), emphasizes the relation among limitations in intellectual and adaptive skills, and describes the environmental influences on the impact of these limitations, and the intensities of supports needed to improve functioning in the community."

The system also departs from previous ones in that "a single diagnostic code of mental retardation is used," if certain conditions are met (e.g., age of onset). Four dimensions are used throughout the definition, classification and systems of support: intellectual functioning and adaptive skills, psychological and emotional considerations, physical health and etiology considerations, and environmental considerations.

Three chapters are devoted to the applications of the definitions. The first discusses educational applications within the context of current laws in education and vocational rehabilitation (e.g., requirements for individualized programs, assessments). In the second, the authors reframe the definition and its "adult services" applications in terms of the new paradigm of ("functional") supports and "community membership," assuming the "nature of systems of support" to include family and friends, nonpaid supports, generic services and specialized services. The third describes social policy, and research and legal applications of the new definition (e.g., eligibility and funding).

Analysis:

The new definition represents an important effort to begin to shift from narrower psychological-environmental based approaches toward a definition and classification which reflects new conceptualizations of service delivery and trends in practices in the field of mental retardation and developmental disabilities. However, as described in the 9th edition, further theoretical and practical integration needs to occur.

Contribution to Conceptual Models:

The revised definition is being used in peer-reviewed journal articles, and in practice in the field ranging from courts (e.g., determinations of capacities for child custody) to community services practices (See, also new 1995 articles in the American Journal of Mental Retardation). The incorporation of supports within the professional definition offers opportunities to move toward new professional practices within education, criminal justice, health care, social welfare as well as mental retardation.

Adaptive skills are based upon 10 areas which are attributed to late 80s developments in functional special education: communication, self-care, home-living, social, community use, self-direction, health and safety, functional academics, leisure, and work. The chapters include specific examples of supports: "psychopharmacological," "behavioral," "supports that can *enhance safety" (e.g., personal safety training, safe and available transportation, criminal record checks), and "health" supports.*

Keywords: psychological assessments, classifications (and diagnoses), supports, mental retardation, (special) education, adult services, community membership, generic and specialized services, etiology, social environment, mental health/mental retardation, behavioral supports, adaptive skills, community functioning, intellectual impairments

Citation: Hayden, M. & Abery, B. (1994). Challenges for a service system in transition. Baltimore, MD: Paul H. Brookes.

Summary:

The edited book is based upon work conducted by the University of Minnesota, Syracuse University and University of Illinois-Chicago on community integration. The work is presented in four parts: issues and methodological approaches in community living research, promoting community integration and social relationships, community services and support issues, and enhancing independence and autonomy. The book contains one of the best descriptive chapters on facilitating integration in recreation sites[33], research on the relationships between service users and workers in homes, highly PAS relevant quantitative surveys on community services in developmental disabilities (e.g., financing, personnel, and systemic design), and presentation of information and research on legal guardianship, multiculturalism and self-determination.

Analysis:

The direct references to PAS occur in the chapter on the financing of community services, basically as funding and program mechanisms in relationship to services (affordable housing and pca services) in the states of New York, Colorado, and Wisconsin. In contrast the study of the massive waiting lists within states for community services asks about family support services and respite, distinguishes between residential services, supportive living or semi-independent living, and describes competitive and supported employment, adult day training and habilitation, case management and transportation.

Each of the chapters has specific implications for the development of PAS for people with mental retardation and developmental disabilities. These range from the current ways in which recreation and leisure support and integration are conceptualized (E.g., pas within context of community organizations), to the study on staff turnover and wages of direct care staff (parallel studies were not available on PAS wage, benefit and turnover issues), and the assessment and enhancement of quality services (e.g., increased promotion of service coordination and

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[33] *Also see articles in JASH (e.g., 1986, 1989) and Mental Retardation (e.g., 1993a, 1993b) (e.g., mainstream participation constraints, leisure preferences, independent leisure center use, Special Olympics).*

casemanagement as monitoring role in contrast to user-directed PAS). The chapter on homes and homelife also include a section on the relationship between service users and agency workers which have important implications for PAS designs.

Contribution to Conceptual Model:

For the development of the conceptual "model," the book is organized around six aspects of quality of life: presence in the community; health, safety and basic comfort; opportunity for personal growth and development; social relationships; valued community participation and personal self-determination. Each of these areas can be explicitly reviewed in relationship to the principles of the new model(s).

***Keywords:** self-determination, social relationships, quality of life, community living, community participation, community integration, community supports, independence*

***Citation:** Arnold, M. & Case, T. (1993). Supporting providers of in-home care: The needs of families with relatives who are disabled. Journal of Rehabilitation, 55-59.*

Summary:

The article describes a study of the "financial resources and needs ("and coping abilities") of ("more than 750") families providing home care to relatives with (diverse) disabilities" in eight counties in Southeast Georgia.

Twenty percent of the survey questionnaires were completed by persons with disabilities in independent and semi-independent living arrangements, 79% families and relatives, and 2% foster or adoptive families; of the families reporting 60% were white, 39% were black and 1% were Asian or Hispanic. The authors report that most often the primary disability was speech or mental retardation, and most families represented the "working poor."

Twenty six percent of the families ranked financial assistance as the most urgent need, followed by medical care (7%) and job placement (6%). Dental care, respite care, transportation, special equipment and supplies, and speech therapy were each listed as most urgent by 4% of the families. Attendant care was not in the top three tiers of needs, and was one of 19 (plus other) need categories reported. Attendant care was also seen as distinct from in-home nursing services, homemaker services, home training, emotional support, recreation and therapies.

The article concludes with a discussion on financial assistance (voucher-reimbursement systems, Medicaid, TEFRA waivers), medical care (advocating for existing medical supports, program advocacy) and job placement (supported employment as part of Medicaid waiver applications, Job Training Partnership Act), and with a call for Independent Living Centers to facilitate inter-agency collaboration and administer family support programs.

Analysis:

The study is significant in ranking attendant care, in the context of families' (i.e., defined to mean people living in semi-independent and independent settings) perceived "most urgent" needs with non-service areas (finances, medical care and jobs) ranked as most significant. The article does not discuss attendant care, specifically, for example, how assistance might be an avenue to employment or medical care. The Medicaid waivers are also a source for funding of PAS, and the independent living centers are one of the providers. Inadequate information is available to assess the rigor of the questionnaire study.

Contributions to Conceptual Model:

The article frames PAS in the way it has been typically thought about related to people with physical disabilities, health assistance and the roles of independent living centers. However, it is significant in starting to reframe PAS as family support, with the definition of families to mean people living in independent settings as well as birth families.

***Keywords:** attendant care, in-home care, community services, financial assistance, employment, medical care, family support*

***Citation:** Dunst, C., Trivette, C., Starnes, A.L., Hamby, D. & Gordon, N. (1993). Building and evaluating family support initiatives: A national study of programs for persons with developmental disabilities[34]. Baltimore, MD: Paul H. Brookes.*

Summary:

Written by people with a commitment to family empowerment, the book describes a conceptual framework, methodology and findings from a national study of family support initiatives. Operationally, the authors define family support as "directed at reforming existing policies and practices so that major situations will improve family functioning by their support..(and)..empower (people) to act for their own good and the good of their immediate

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[34] Also see, for father involvement, Davis, P. & May, J. (1991). Involving fathers in early intervention and family support programs: Issues and strategies, Childrens' Health Care, Vol. 20(2), 87-92.

For empowerment and fmaily supports, see Dunst, C., Trivette, C., Davis, M. & Cornwell, J. (1988). Enabling and empowering families of children with health impairments. Childrens' Health Care, 17(2), 71-81. For an analysis of 223 parent-oriented and family-oriented articles from 1980 to 1991, see Trivette, C., Dunst, C., Allen, S. & Wall, L. (1993). Family-centeredness of the Childrens' Health Care Journal. CHC, 22(4), 241-256.

Also, literature on siblings, roles of women in caregiving, early intervention/early family support with young children, and family support policy.

support..(and)..empower (people) to act for their own good and the good of their immediate community" (Kagan & Shelly, 1987).

Family support movements are the family resource coalition, state-government established family support programs, family-centered health care practices, family-focused early intervention practices, and family support programs for people with develop-mental disabilities. These share the belief that "supporting and strengthening families ought to be a major outcome of family support and family resource efforts." Six major family support principles were used in the study: enhancing a sense of community, mobilizing resources and support, shared responsibility and collaboration, protecting family integrity, strengthening family functioning, and proactive human service practices.

The author's conceptual scheme "links political climate, policy and practice, policy implementation, and outcome analyses, and several sets of criteria and standards for judging the adeqaucy of family support policies and practices" (p.15). The authors developed a coding and ranking system, and analyzed comparisons between and within entities to establish whether "similar or dissimilar approaches to family support and policy/practice implementation produced like or unlike results." The authors developed extensive categorization schemes (e.g., types of initiatives, elements of initiatives) and reported on analyses of federal legislation, state level initiatives, state program characteristics, community-based program initiatives, and casemanager and family transactions.

Analysis:

From the perspectives of PAS and family support developments, several points are particularly relevant. First, the authors offer some of the first analyses of the linkage of policy and practice at different levels (federal, state, regional, worker/agency, and family) regarding these growing initiatives. Second, the authors frame family support within the field of developmental disabilities in the context of national family support movements. Third, the study shares some of the same areas of strength and of concern as its predecessors (e.g., "family outcome" as the mother's experience of casemanager practices; lack of integration with other governmental family policies of particular significance to "vulnerable" families; lack of distinction between adults and children living at home with family). Finally, the book does not integrate PAS in the context of family support.

Contribution to Conceptual Model:

The study offers multiple contributions to PAS development: (1) the essential need to examine basic assumptions underlying the family support movements in the US as they relate to "families at risk" and "children at risk"; (2) potential elements of research design regarding PAS at multiple levels (federal, state, regional, agency, person); and (3) critical need to reframe family-case-manager transactions, particularly as related to user-directed PAS.

***Keywords:** family support, community support, developmental disabilities, family-centered health* *care, family resources, early intervention, state/federal policy, casemanagement, outcome research, financing, legislation, family functioning, community-based practices, human services*

Citation: Tate, D., Forcheimer, M. & Daugherty, J. (1993). Insurance benefits coverage: Does it affect rehabilitation outcomes? Journal of Rehabilitation, 6-10.

Summary:

The study reports on the effect of insurance benefits coverage (e.g., return to work), "provided by four payors of rehabilitation (i.e., automobile no-fault, private, workers' disability compensation, Medicaid) on the rehabilitation outcomes of 111 spinal cord patients (with people with cognitive deficits or psychiatric diagnoses excluded)." The authors report that catastrophic payors (53% of the sample) "often provide better coverage for benefits to live independently (i.e., accessible housing, transportation, personal care services)."

Three instruments (brief symptom inventory, DeJong's restrictiveness of living arrangements scale and an activity scale) were used to guide interviews during hospitalization and one year post injury (activity scale only). The results suggested that the insurance payor was not a strong predictor of these outcomes; "age, neurological level of injury, and pre-injury restrictiveness of the living situation were the best predictors of post-discharge activities"; and that "post-discharge psychological distress was best predicted by the extent of personal care attendant services received during the first year."

The findings on pcas were considered "unexpected" with persons with higher hours (paid assistants and mostly non-paid family and friends) reporting higher distress. The authors suggest that coping with significant dependency on others might be the source of the distress. The article concludes with recommendations to professionals: developing patients' motivation and self-initiative, education of patients and families about pcas (recruitment and management, formal help and occassional assistance from friend), and interdisciplinary interventions to restore independence, and suggestions on several research avenues (e.g., paid and non-paid pcas and its effect on outcomes such as work productivity; longitudinal effects of insurance sponsorship).

Analysis:

According to the authors, this is the second study on insurance coverage and its effects on persons with spinal cord injury. The findings on the relationship with pcas and psychological distress are significant, with the fact that most assistants were family and friends, particularly worth pursuing. The authors' interpretation is consistent with forced care situations where the person may also become viewed as a burden, and subsequently, experience additional stress. Insurance coverage has also been an important avenue for paid services for people with cognitive disabilities, such as brain injuries, though often not through paid pca models.

Contributions to Conceptual Model:

The author's recommendation on the need for further research on the relationship between (paid and non-paid) pcas is also significant in the fields of mental retardation, brain injury and psychiatric disabilities (and is not adequately covered by the existing family research with interpretations from the perspectives of parents as caregivers and surrogates). Insurance coverage of pcas in the area of "cognitive" disabilities needs to become a standard, accepted form of health coverage.

Keywords: *rehabilitation, financing, insurance, supports, attendant services, disability management, long-term health care, independent living*

PERSONAL ASSISTANCE SERVICES IN THE FIELD OF PSYCHIATRIC DISABILITIES

According to leaders in the psychiatric survivor movement, very few examples of user-directed personal assistance services exist (See, Racino, 1995; Chamberlin, 1994). With children and their families, PAS has not been a central part of childrens' mental health, with the closest analogs of "wraparound" services and in-home (non-therapeutic) family support services (See, also Friesen, 1994). A user-directed "model" could be revolutionary, since it would place control in the hands of people, who by definition of their disability, are often considered to be incompetent (Chamberlin, 1994; Unzicker, 1994).

This section is organized around:
* two personal perspectives on personal assistance services and independent living;
* an essay on the (consumer) self help movement in mental health, including personal attendants as an individualized support;
* an article on psychiatric rehabilitation (inclusive of intervention studies);
* a special journal issue on supported housing with references to issues on supported education;
* three articles on employment, inclusive of reasonable accommodations, consumer-initiated job search, and research on supported employment;
* two articles on childrens' mental health from two national research and training centers, and another for parent information centers for children with challenging needs;
* a book chapter on prevention, for discussion about "systems" versions of pas;
* one article on system of care for children and adolescents with emotional needs and (public policy).

Citation: Stewart, L. (1991). Personal assistance services for people with psychiatric disabilities. In World Institute on Disability, Personal and political perpectives on personal assistance. Oakland, CA: WID.

Summary:

One of the essays describing personal assistance services for, by and/or with people with psychiatric disabilities: (1) shares an overview of the mental health system/medical model and why it doesn't work, is "offensive," "archaic" and "unacceptable" to many people and how "clients are forced to follow the service dollar"; (2) provides a way of thinking about assistance as physical, cognitive and emotional tasks; and how PAS could allow persons to live independently; (3) describes a personal account of PAS in employment; and (4) argues for a non-professional approach to PAS and a lack of "forced dependence" on family and friends. The author argues for a national PAS program which includes principles from the Independent Living (IL) Movement, such as consumer control and cross-disability services, and affords all people with disabilities the opportunity to live, work, go to school, and be (with) friends and family in *their communities.*

Analysis:

As one of the leaders in developing PAS in "psychiatric disabilities," the essay describes her personal experience, while also offerring concrete areas (e.g., employment, non-professional approach, types of tasks) which need to be addressed if PAS is not to become like other community-based service models. The authors' commitment to consumer control, cross-disability and integration, together with her understanding of current practices dominant within the mental health system, are valuable contributions to strategically thinking about national PAS development.

Contribution to Conceptual Model:

The author's explicit commitment to approaches which do not force dependence upon family and friends (which many of the newest approaches to supportive services inadvertently do) has important practice and policy implications for PAS. The principles, which are not currently translated into practice nationally, form an important base for further PAS discussion, including among the consumer leadership within and across movements. The article provides an example of PAS in employment, which can be understood also in the context of reasonable accommodations and the Americans with Disabilities Act. Promoting the acceptability of paying for "emotional" and "cognitive" tasks and for translating these tasks (with consumer control) remain as practice and policy issues.

Keywords: *independent living, mental health system, consumer control, personal assistance, psychiatric disabilities, cross-disability; strategic planning*

Citation: *Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we are going*[35]*.* ***The Journal of Mind and Behavior****, Vol. II, No. 3-4, 323(77) - 336(90).*

Summary:

The review and update article by Judi Chamberlin discusses the guiding principles of the "ex-patients' movement," and the historical development of the movement through the transition

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[35] *see also, National Association of State Mental Health Program Directors (1989). Position paper on consumer contributions to mental health service delivery systems. Burlington, Vt: The Center for Community Change through Housing and Support.*

Ridgeway, P. (1988). The voice of consumers in mental health systems: A call for change: A literature review. Burlington, Vt: The Center for Community Change through Housing and Support.

to self help, empowerment, and advocacy.

In the section on principles, the article includes the rationales for exclusions of mental health professionals from the movement; frames how people moved from internalized oppression to setting their own priorities; highlighted self-determination, self-definition, mutual support and control of services as critical principles; and also consciousness raising as an ongoing process. In the historical development in the US, Judi Chamberlin raises many issues which involve:

- *the roles of people within the movement ("leadership role of "ex-patients") and local groups;*
- *false assumptions of the "system" (lifetime dependence or control; perpetuation of labeling, forced drugging and paternalistic control);*
- *interactions with the system (ex-patients "polarized discussions," tactical cooperation or confrontation; legitimization of anger toward the mental health system; experiences of abuse and distrust; simultaneous involvement with professionally run programs);*
- *issues with alternative treatment (alternative treatments which imply authoritative relationships and derogatory labeling; need for changed power relationships between patients and psychiatrists);*
- *movement to "empowerment" (passive service recipient to advocate, representing needs of clients; self help as concept not program model - thinking of self and world in new ways; counter "consumerism" and the defining of experiences by others);*
- *definition of treatments (involuntary) as violation of liberty and right to control one's own body and mind;*
- *advocacy (as coequal with self-help; citizenship rights to end commitment, forced and involuntary treatment; right to refuse treatment; liberation perspective as a threat);*
- *consumer run programs (advocacy and self-help alternatives to the system; clients in new roles as service providers)*[36]*;*
- *funding patient-run programs as part of community support);*
- *movement toward "alliances" (with people with physical disabilities, the poor, other countries on health care, housing);*
- *personal care attendants (as an individualized support) and people with psychiatric disabilities in the ADA;*
- *changes in community (more egalitarian structures with shared decisionmaking; right of freedom of choice); and*
- *systems (power of psychiatry; funding controversies).*

Analysis:

The author highlights numerous central issues which have applicability to the relationship

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[36] *See, also, Ebert, G. (1990). Panel presentation on "What are the meaning, characteristics and dimensions of support." Syracuse, NY: Syracuse University.*

between the self-help movement(s) and the development of new forms of personal support and assistance. As a 1990s article, it represents an excellent overview of the ex-patients' movement based upon learned or experienced perspectives and succeeds as a "voice" in the movement.

Contribution to Conceptual Model:[37].

Of particular significance for this analysis is the definition of personal care attendants as an individualized support within the movement and support of alliances outside of disability in contrast with service-user concerns with alternative treatments and consumer-run programs. From a qualitative research perspective, the nature of the relationship between people and "services," "systems," "policies" and "communities" remains a significant one in the design of PAS.

***Keywords:** psychiatric survivors, self help, advocacy, mental health, consumer movement, mutual support, housing, public policy, personal assistance, autonomy*

***Citation:** Wehman, P., Revell, G., Kregel, J., Kreutzer, J., Callahan, M. & Banks, D. (1991). Supported employment: An alternative model for vocational rehabilitation of persons with neurologic, psychiatric, or physical disability*[38]. *Archives of Physical Medicine and Rehabilitation, 72, 101-105.*

Summary:

The article reports on a study of 278 persons with significant functional limitation who had the following primary disabilities: chronic mental illness, cerebral palsy, traumatic brain injury, and dual diagnoses of mental retardation and chronic mental illness. "Fewer than 40% of all groups were living independently before starting the supported employment program," with men compromising most of all groups except people with "dual diagnoses."

The findings are presented in terms of employment outcomes (349 placements made for 278 individuals, mean hourly wage ranging from $3.75 per hour for people with dual diagnoses to $4.66 per hour for individuals with cerebral palsy), type of work performed (e.g., food service and janitorial/custodial for persons with chronic mental illness and dual diagnoses, and clerical/office work for persons with traumatic brain injury and cerebral palsy), type of staff intervention in 8 service categories (active and inactive time on site, travel and transport,

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[37] *See, research program (literature review, focus groups, case studies and study circles) on personal assistance services at Boston University RTC on Psychiatric Rehabilitation. No participant observation studies are included.*

[38] *See also, Anthony, W.A. & Blanch, A. (1987). Supported employment for persons who are psychiatrically disabled: An historical and conceptual perspective. Psychosocial Rehabilitation Journal, 11(2), 5-23.*

consumer training and program development, direct and indirect employment advocacy, and consumer screening and evaluation), and employment retention (14 categories of "reason for separation from employment" which distinguished whether the employer or client initiated).

The authors conclude that "different aspects of supported employment must be emphasized when applying the model to groups of individuals other than those with mental retardation." The lack of independent living did not preclude these individuals from successfully obtaining and maintaining competitive employment. The results indicate variations across the groups in employment outcome and type of work, services provided by employment sepcialists and employment retention.

Analysis:

The article is based, in part, on the assumption that a model of service for one categorical disability group (people with mental retardation) can be modified for other disability groups (e.g., people with traumatic brain injury). It offers one of the few analyses on cross-disability supported, competitive employment of people with significant disabilities. In relationship to PAS, the article provides a comparative cross-disability analysis on key features of "supported employment" for people with severe disabilities and also details features of the models, both on and off-site, which appear to contribute to successful employment. In particular, a relatively high amount of time was spent in employment advocacy for individuals with chronic mental illness and cerebral palsy with a tendency by these groups to "view the presence of an employment specialist at the job site as stigmatizing." "Medical and health problems" were the most frequently cited reason for job separation which may imply a potential role for more traditional pas functions. With people with traumatic brain injuries, unlike the other groups, "only 38.1% of the separations were initiated by the clients" and they were most likely to "display inappropriate behavior."

Contribution to Conceptual Model:

The supported employment movement is a critical base for analyzing how personal assistance services relates both to this paid model which has been adopted in states and codified in law; and to the relationship between the movement to natural supports (e.g., coworkers, employer assistance), enlarged roles of job coaches (outside the work site), and employee-directed and initiated paid and unpaid services. Specifically, the elements of employment advocacy, non-stigmatizing pas off the job site, and pas related to health, medical and behavioral need to be available. The article does not discuss other significant aspects of the supported employment model (and its view of the workplace, and the roles of employers) which are relevant for the further development of PAS.

***Keywords:** employment, (vocational) rehabilitation, reasonable accommodations, Americans with Disabilities Act, workplace culture, advocacy, natural supports*

Citation: *Deegan, P. (1992). The independent living movement and people with psychiatric disabilities: Taking back control of our own lives.* **Psychosocial Rehabilitation Journal**, *15(3), 3-19.*

Summary:

Starting with the quote that "compliance is not the road to independence," the article is based upon the author's efforts to "conceptualize and pilot a completely consumer-controlled and consumer-run program for people with psychiatric disabilities" in the Northeast. The author distinguishes among the concepts of independent living (il) as a social justice and civil rights movement, a "lived" philosophy, and the independent living centers as service delivery and advocacy centers, and describes what il can mean for people with psychiatric disabilities. As a movement, she supports grassroots organizing first among the "community of people" (e.g., people with psychiatric disabilities) to avoid the pitfall of the "same mold that worked with people with physical disabilities." This does not negate discovering that all people with disabilities face barriers to independent living: stigma, lack of affordable housing, work disincentives, inferior health care, poverty, unemployment and segregation.

As a philosophy, she describes the central attitudinal barrier as being "the assumption that people with psychiatric disabilities cannnot be self determining" which "must be understood as a barrier that pervades and permeates mental health policies, procedures and programs." Cogently, she translates each of the IL principles into possible practice implications, such as distinguishing between disability package plans which can be 'spirit breaking' from having a disability, and social and interpersonal environmental barriers, including lack of options for choice and for "deciding on whom we will choose to rely on for support."

The author attests that the independent living centers initially grew out of the "revolutionary concept of training people to acquire personal care attendants and subsequently became places where peer counseling, shared expertise, individual advocacy and legal monitoring occurred. Of utmost importance, the author espouses that "new services" must "grow out of our emerging sense of what it is we need to gain control over our lives." As an example, she explained how "we are understanding that one of the most central issues in our lives is pscyhotropic medications;" that there is a tremendous need for advocacy and skills training in the state hospitals; and people might use a "psychiatric living will" or "health care proxy."

Analysis:

A moving writer, the article represents one of the best descriptions of the independent living movement and its meaning in relationship to people with psychiatric disabilities. In relationship to pas, it describes how as early as 1974, "personal care attendants" (pcas) were starting to be used by people with physical disabilities in apartments outside of institutions and how "we learned to hire, interview, and train our own pcas to do what we wanted, on the schedule we wanted it done" and to have that publicly funded.The service aspects of PCAs ("between 1974 and 1979 we went from 10 people using pcas to probably close to 200") are *contextually embedded within the larger IL movement and its environmental, social, personal, and societal context. Similar to her counterparts, she supports training within the state hospital settings, versus movement toward full inclusion.*

Contribution to Conceptual Model:

The article's contributions to the model development include: (1) conceptualization and development of services by people with psychiatric disabilities; (2) support for a user-directed approach to PAS; (3) conceptual tie between the assumption that people with psychiatric disabilities cannot be self-determining with the critical importance of its translation into policy and programs; (4) components of il which may be inseparable from pcas, grassroots organizing, personal advocacy, and group self-defining of "services"; (5) central issue of psychotropic medications, and the strategy of health care proxy; and (6) the environmental and personal contexts which are often missing at the level of service practice and service policy development. The article, in its presentation alone, raises substantially different ways of thinking about model development than the one being pursued here.

Keywords: *independent living, psychiatric disabilities, consumer control, independent living programs, empowerment, consumer movement, autonomy, advocacy, community support services*

Citation: *Duchnowski, A. & Friedman, R. (1990). Childrens' mental health: Challenges for the 90s[39]. __Journal of Mental Health Administration__, 17(1).*

Summary:

The authors provide an overview of the status of childrens' mental health highlighting Knitzer's 1980s "landmark study" on children and adolescents in need of mental health services, the development by the National Institute of Mental Health of its Child and Adolescent Services Program (CASSP), the role of state child mental health leaders, and state planning as framed by the Mental Health Planning Act, also noting the roles of the newly formed Federation of Families, the National Mental Health Association, the Childrens' Defense Fund, the Childrens' Welfare League, and the Association of Child Advocates.

Seven major challenges are identified: training and human resource development (E.g., discrepancy between academic programs and public mental health systems needs), funding for services, research (inclusive of effectiveness of innovative approaches, effects of different reimbursement mechanisms and funding strategies, and services to minority children and families), interagency collaboration (joint systems planning, financing and collaborative state and community programming), overall service system development ("integrated community-based system of care" for categorical group), advocacy (e.g., funding, quality of care, programmatic and policy approaches for younger children) and children at risk (with substance abuse, cocaine babies, homeless children and families, child abuse and neglect, and HIV-infected children).

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[39] *Also, see, Annual Research Conference proceedings on childrens' mental health; for example, field studies on cash assistance on families, cross-systems efforts at "individualized tailored care," transition, regional and state models, and child abuse and neglect.*

Analysis:

Co-authored by two people committed to both research and service development in childrens' mental health, the article provides a good summary of directions, primarily from service, systems, and research perspectives. For the purposes of PAS development, the authors describe already established systemic approaches and service models which are viewed as needing to be "refined" and made more available and established on the local and state levels. The closest parallels to PAS mentioned in this article are wrap-around, intensive home-based interventions, or multiple, flexible services for youngsters with the assumption of an "individualized treatment plan." Strengths are the work towards cross-systems collaboration as an effort to address the needs of children who otherwise may be at risk (e.g., juvenile justice, child welfare) and efforts to develop families as allies.

Contribution to Conceptual Model:

Personal assistance service (PAS) for (by or with) children and youth in the mental health arena are potential, yet unactualized areas of research at the childrens' mental health research and training centers (e.g., Florida, Oregon). Yet, many of the concepts of independent living and youth-initiated efforts are instead separated from intensive, home-based services and wrap-around services and child-centered, professional interventions. Almost all aspects of the systems based work is relevant to PAS state level development.

Keywords: childrens' mental health, community support (service) systems, financing, community services, individualized treatment; child welfare; state planning; children-at-risk

Citation: Shoultz, B. (1992). A new challenge: Responding to parents of children with emotional, behavioral and mental disorders. Boston, MA: Federation for Children with Special Needs.

Summary:

Prepared through a contract with the Federation for Children with Special Needs, the paper describes how parent training and information centers in this country can respond to "requests for assistance from families of children with emotional, mental or behavioral disorders." After describing who the children are (see RTC on Family Support and Childrens' Mental Health)[40], and their common experiences, strengths and needs, the author suggests that

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[40] See, Friesen, B. (1993). Family support in child and adult mental health. Portland, Oregon: RTC on Family Support and Childrens' Mental Health, Portland State University.

the PTIs can play the following roles: (1) demystification, (2) information, (3) support, (4) vision, (5) recognition of parents' expertise, (6) communication, (7) awareness of cultural and class issues, (8) educational rights, and (9) introducing parents and other family members to each other. The article is accompanied by vignettes describing five families.

Analysis:

As part of a growing commitment to the nation's 7.5 million children with mental health needs and their families, the paper is written in a way to "demystify" the perceptions of children who may be abused, become involved in the criminal justice system, may end up in psychiatric institutions or segregated classes, and whose lives and those of their families may be disrupted, but who share the "positive characteristics that any other child can have."

The paper's greatest strength is in framing childrens' mental health within a non-medical framework, inclusive of a vision of societal change which is respectful to the families and their children. In terms of services, the author supports changed relationships with children and their families, and frames the problems as families being forced to choose between inadequate assistance that will not meet their needs and unneccessarily restrictive services.

Contribution to Conceptual Model:

***Information access.** The author strongly supports the role of information access, including on educational rights, on "dealing with difficult behaviors, on relationships and on moving into adulthood," on "how best to support their child," and on the crucial role of listening "as parents."*

***Children's opinions in decisionmaking.** The author supports the involvement of children in decisionmaking and the making known of their views, and the role of the PTIs in "ensuring that the child's opinions are sought on the issues impacting his or her own future." However, the article clearly supports the recognition of parents as knowing their child's needs and strengths.*

***Race, class and cultural awareness.** The author describes their role in professional interpretations of behaviors, and in the "examination and questioning of professional practices."*

***Keywords:** families, childrens' mental health, parents, emotional disturbances, behavioral disorders*

***Citation:** Friesen, B. (1993). Family support in child and adult mental health. Portland, Oregon: Research and Training Center on Family Support and Childrens' Mental Health, Portland State University.*

Summary:

Prepared for a state family support conference, the author presents her overview of the status of developments nationally in family support related to both children and adults in mental health. The article highlights historical perspectives (e.g., the recent emergence of two new national family support organizations, supporting roles of foundations), the emergence of family support principles and challenges, the analytical theories guiding practice (with a bias toward an ecological approach), the common experiences of families (e.g. prolonged uncertainty; dealing with difficult behaviors; financial problems) and their family support needs, the comparisons between children and adults in family support, family support initiatives, programs and groups, family-focused mental health legislation, existing research (inclusive of children at-risk of abuse or neglect), and policy implications.

Family support needs were defined as including emotional support, information access, respite, crisis service, behavior management assistance (44% of families in one study feeling threatened at one point by their children), education, support with out-of-home placements of their children ("residential treatment" as extension of family), transportation, homemaker service or other in-home service, financial planning, housing, casemanagement /service coordination, and life planning assistance.

Research in areas such as "respite" were considered to be in infant stages; few distinctions were seen between adult and children family support needs (e.g., "no statement of principles of family support were identified in the adult mental health literature; "population of adults is more circumscribed" with those with "major mental illness"); families were seen as sometimes accessing public child welfare to gain access to publicly funded mental health services; and family-centered services were endorsed.

Analysis:

The article is excellent in presenting viewpoints as represented in one segment of the parent, professional and childrens' mental health movement in order to move forward the agenda of the recognition and the policy and practice translations of family support. Although the paper theoretically addresses both children and adults, it concludes with family research in childrens' mental health highlighting themes ("family advocacy") and constituencies (family members concerned about child functioning) which on the surface do not include adult children as participants or collaborators.

Contribution to the Conceptual Model:

Families with children and adults with emotional needs are already included in the state family support programs in places like New Hampshire, where the paper was presented. Adult children, however, may experience family support very differently from their parents (or caregivers); for example, feeling kept at home against their will or family advocacy as representing other than their wishes (parent versus adult child interests). The out-of-home *placement of children, and family support as an entry into these forms of placements are also of substantial concern (e.g., children who are legally barred from adoption when parents have abandoned them). Significant issues, such as the inclusion of parents with significant emotional needs themselves, as part of the family support movement, also are not explicitly addressed.*

Keywords: *family support, childrens' mental health, adult mental health, public policy, casemanagement, advocacy, parent-professional collaborations, mental health theory, community services*

Citation: *Rogers, E., Anthony, W., & Jansen, M. (1988). Psychiatric rehabilitation as the preferred response to the needs of individuals with severe psychiatric disability[41]. **Rehabilitation Psychology**, 33(1), 5-13.*

Summary:

The article briefly describes the emergence of psychiatric rehabilitation and its relationship to people with severe psychiatric disabilities, especially the two groups which were the "sources of public policy debate" (people who are homeless and young adults with psychiatric disabilities)[42]. At least one definition of "chronic mental illness" specifically refers to the "erosion" or the "prevention" of the development of "functional capacities" in relationship to three or more areas of daily life: personal hygiene and self care, self-direction, interpersonal relationships, social transactions, learning and recreation that "erode" or "prevent" economic self-sufficiency.

Briefly reporting on the demographics as available from the Community Support Program of the National Institute on Mental Health (1984), the authors note that of the 93,214 CSP clients served nationwide, the majority of CSP clients lived in private homes or apartments (57%), tended to never be married (53%), were diagnosed as having schizophrenia (59%), received Social Security Income (44%) and may not be representative of all persons with psychiatric disability. No more than 20-30% were competitively employed (Anthony, 1979), with 52%-92% as high school graduates and 15-60% having attended college.

Psychiatric rehabilitation, "like its counterpart in physical rehabilitation", consists of two "intervention components" of "skill development" and (environmental) "support development" to better enable people to "function in their roles of choice" with "societal rehabilitation" designed to change "the system" (e.g., targeted job tax credits). Based on a review of over 30

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[41] Also see, status of employment services, e.g., Exemplary practices in employment services for people with psychiatric disabilities (1993) by the National Association of State Mental Health Program Directors.

[42] People with psychiatric disabilities and substance abuse issues have taken on comparatively increased public policy importance in recent years.

studies on the impact of skill and support development interventions on client disability and handicap, Dion & Anthony (1987) concluded that these interventions have a positive effect on "client rehabilitation outcome" (also see, Anthony & Margues, 1974). The authors (1987) concluded with a note that the research is set to move from the "development and evaluation of innovative rehabilitation programs" to "experimental studies of replicable, measurable psychiatric rehabilitation interventions."

Analysis:

Psychiatric rehabilitation is relatively well known as a set of intervention strategies in both (state and private) institutions and in community agencies (though defined and implemented differently than described in this article). The article provides a good overview of the status of psychiatric rehabilitation as of the late 1980s, and is useful in its explicit description of its "intervention components" (skill and environment) paralleling physical rehabilitation, and the importance of demographics and public policy populations to the development of any new service or policy models. Psychiatric rehabilitation has tended to have less emphasis on community change, support, and on moving from institutions to regular community life (In contrast, see Murphy, Racino & Shoultz, 1992).

Contribution to Conceptual Model:

The intervention studies (1987, 1974) cited in the article also can be analyzed from the points of view of user-directed approaches to PAS and outcomes as defined by the service user. For some people in institutional settings, the conceptualization and implementation of pas outside the institutional settings has not taken place (though approaches to community support services for individuals with the both mental retardation and psychiatric disabilities and "chronic mental illness" have occurred in the USA).

Keywords: psychiatric rehabilitation, (severe) psychiatric disabilities, skills and environmental supports; special populations; service efficacy and outcomes research; deinstitutionalization; public policy

Citation: National Conference of State Legislators. (1988). Mental health financing and programming. Colorado: NCSL.[43]

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[43] See also, definitions of personal care services (HCFA, 1993; Community Support Network News, 1993) as "grooming, personal hygiene, assisting with medications, and the preparation of meals when performed for the recipient, as opposed to teaching the recipient are not properly defined as rehabilitative services" (but may be considered under the separate personal care services benefit option).

Community Support Network News also targets particular issues, such as Rehabilitation and Case Management under Medicaid (Winter 1993), Rehabilitation Act Amendments (Summer 1993), Outcomes Research (Fall 1993), Supported Education (Fall 1994).

Summary:

The book describes the transition of the mental health system from one relying on long term hospitalization to community "care." The "major issues" confronting policymakers (e.g. service delivery, civil commitment, special populations), basic needs (e.g., housing, financial support, meaningful activities), disability services (e.g., treatment, social services, medication monitoring) and "integrative services" (e.g. advocacy, community information, and case services) are discussed as part of the "array." Delivery and coordination approaches are illustrated by state examples ("single point of authority," "passing the buck on difficult populations," "broker, "cluster groups and cooperative agreements").

The book describes evaluation in the context of public policy, including the use of "performance measures." Mental health financing is reviewed, including (federal) entitlements, income support, block grants and housing initiatives, programmatic barriers and efforts to address (e.g., PASS for "work goals"), resource expansion strategies (increased eligibility, certified providers, reorganized service delivery, regulations, grant and housing funds) and financing strategies at the state and local levels (e.g., managed care, reshifting institutional and community funds, mandated health insurance coverage, risk pools, reuse of surplus institutional property, and entrepreneurship). The challenges for the future (Year 2010): nontraditional funding streams with increased role for private sector, decentralization and self-help programs, and shift from federal to state responsibilities with states reducing direct service provision.

Analysis:

The book reviews perennial public issues (e.g., the current re-emphasis on state block grants) and strategies such as managed care, which increased as a state focus in response to anticipated health care reform. Particularly important for this review were the definition of "self-help" as a program, "involuntary out-patient treatment" as a threat to personal life quality (e.g., non-professional and user-directed pas), and the integrated service delivery patterns, none of which appear sufficient to move toward newer forms of relationships among people, local communities, services and systems. Local community and community organizations, the relationships between formal and informal systems, and person-centered approaches, inclusive of personal relationships, are not described in this context.

Contribution to Conceptual Model:

From the perspective of long term support services (e.g., PAS), a broadened definition of PAS might include service types that fall in numerous areas (and with diverse funding): home health services (as part of treatment services), professional mental health service types (e.g., self-

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Specific financing research studies and technical assistance reports are also relevant (E.g., the Center for Substance Abuse Treatment's Medicaid financing for mental health and substance abuse services for children and adolescents).

medication training), homemaker services, or habilitation/vocational/social services. To date, successful reversal to user-directed (or negotiated) services for, by or with people with significant disabilities of even one type, in relationship to one disability population group, or financing source has not occurred.

Keywords: *health care financing, model service systems, mental health, service delivery, treatment, disability (public) policy, evaluation, legislation, deinstitutionalization, human service organizations; special populations; programming; housing and employment*

Citation: *Rowland, R., Gilliland, C., & Moxley, D. (1993). A consumer-initiated job search training program.* ***Journal of Rehabilitation****, 59(4), 61-66.*

Summary:

The article offers an example of how one state (Ohio) moved toward "consumer-operated demonstration projects," including ties among the National Institute on Mental Health (NIMH) initiatives, state gubernatorial, legislative and bureaucratic support, and local consumer program goals. It defined and operationalized consumer-operated services as "a program, project, or service planned, delivered and evaluated by a consumer group based on needs as defined by the consumer group."

The paper briefly describes consumer-initiated supports, the compatability between the consumer movement and psychosocial rehabilitation regarding client self-determination, and "consumer-operated," community support programs funded by the Ohio Department of Mental Health. Twelve projects in the state between 1985 and 1990 included social clubs, consumer advocacy, restaurant, a women's support network, a landscaping and cleaning business, vocational training and employment, peer supported job search and employment alternative, and a wellness club promoting general health.

Highlighting a program of vocational development, employment training, job development and job search opportunities, Friends Reaching Out for Friends, a consumer-professional collaboration, was operated by an existing organization selected through a request for proposal process. In particular, the article reports on the aims, structure, process and content of the job search modules for the "consumer-initiated training." The article concludes with suggestions about strategies "consumers" may use for initiating their own supports.

Analysis:

The authors chose to devote most of their resources to describing one of the twelve diverse programs in the state, with the primary emphasis on the training program which appeared to be substantially similar to models not developed by consumer groups. The program would be distinguished in being "run by consumers for consumers" (translated into peer supports to reduce isolation) and the "membership's self defined needs" (e.g., assistance from professionals for vocationally related skills through review of proposals with selection of an existing organization).

The aim of the training was for participants to have the tools to support their own self-directed job search (i.e., a preparatory program for tool and skill development; professionals as trainers; use of adult learning principles; and work readiness model).

Contribution to Conceptual Model:

The major contributions to the development of PAS are in highlighting similar issues which need to be addressed, particularly in the mental health field: (1) the importance of distinguishing among the concepts and practices reflected in the language of consumer-operated and consumer-initiated supports, with particular emphasis in implementation on the potential of co-optation and on the vision of what is possible versus what currently exists; (2) the distinctions between programs "run by consumers for consumers" and its service translation into funded peer support models often with professional definitions; (3) the distinctions between models based upon "membership needs" and those based upon person-centered approaches, and (4) training models developed with a focus on a specific categorical disability group versus the incorporation within existing job training. Specifically in relationship to PAS, it is unlikely to arise as a consumer-initiated support service within this context.

Keywords: *employment, self-help, consumer support services, vocational rehabilitation, mental health; consumer advocacy, peer support, services planning*

Citation: *Stroul, B. & Friedman, R. (1986). A system of care for severely emotionally disturbed children and youth[44]. Washington, DC: Georgetown University Child Development Center.*

Summary:

The monograph, following Jane Knitzer's study on Unclaimed Children and the efforts by National Institute on Mental Health to develop the Child and Adolescent Services Systems Program (CASSP), explores "changing the entire" service systems for "the most troubled children and youth." Defining the concept of the "continuum of care" for severely emotionally disturbed children and youth (in contrast, See, Taylor, 1988) and the need for increased interagency collaboration and coordination across systems, the monograph provides a framework which "states and communities will modify and adapt" to their particular environments with priorities in accordance with their needs.

Considering children to be "unclaimed" by the public agencies, the authors proposed a child-centered (needs of child and family) and community-based system of care, with "individualized services" in the least restrictive, most normative and clinically appropriate environment (LRE) (in contrast to NRE, nonrestrictive environments; see Taylor, Racino,Knoll

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[44] *See, also, Kutash, K. et al (1992). A system of care for childrens' mental health: Expanding the research base (5th annual research conference proceedings). Tampa, Florida: RRTC on Childrens' Mental Health.*

& Lutfiyya, 1987), families and surrogate families involved in planning and service delivery, and advocacy, casemanagement and smooth transitions to the adult service systems.

The framework is "function-specific" with the (service) dimensions of mental health (non-residential and residential), social (e.g., protective services, financial assistance), educational (e.g., assessment and planning), health (e.g., health education and prevention), vocational (e.g., career education, supported employment), recreational (e.g., summer camps, after school programs), and operational (self help and support groups, transportation) represented as areas of need for the child and family.

The monograph describes traditional systems change activities as planning and needs assessment, modifying the mental health system, interagency collaboration, technical assistance and training, constituency building,and local systems development. It proposes an evaluation assessment based upon fiscal policies, statutory base for systems of care, standards, monitoring and evaluation, advocacy and community education, treatment decisionmaking, training and technical assistance, coordination and management, interagency collaboration, community-based nature of system, and planning for the system of care and a systems of care model.

Analysis:

The authors describe one way of conceptualizing cross-service systems design and functioning, which can also be converted from "community-based" to "community" functions (e.g., employment and jobs, neighborhood centers and theater). The monogograph frames systems change based upon assumptions of how communities work, on the relationship between services and families/individuals, on the relationship between different parts of the systems, and on the nature of innovations, values and local "adaptation." Within current contexts, the monograph indicates opportunities for moving away from common practices and systems which harm or ignore youth and their families toward better quality lives (including in interaction with services and systems). The LRE and continuum-based service design (See also, Racino & Heumann, 1992 with elders), and the implementation of "individualized services", have already proven problematic for people with significant disabilities, with a need to reconceptualize all aspects of how services and systems relate to quality lives.

Contribution to Conceptual Model:

The development of personal assistance services (PAS) is also based upon how one conceptualizes services and systems, with this article reflecting more traditional approahces to systems. Current strategies are not (a) always informed by knowledge outside the disability field (e.g., knowledge dissemination); (b) based upon an integration of current knowledge between the relationship of individuals and families with services (e.g., ethnographic studies) and public disability policy and systems approaches; and (c) based upon a changed relationship among individuals, communities and systems (In contrast, see, Racino, 1993).

***Keywords:** adolescence, youth, emotional disturbance/mental health, community support, health,* *recreation, education, vocational, social services, systems management, casemanagement; public policy; systems change*

Citation: *Special issue: Supported housing: New approaches to residential services. (1989).* ***Psychosocial Rehabilitation Journal****. Boston, MA: Center for Psychiatric Disabilities*[46].

Summary:

Supported housing in the field of mental health (See, also work by Carling et al, 1993) is the nearest parallel to supportive(ed) living in the field of developmental disabilities. A special issue describing this approach to residential services highlighted supported housing from diverse perspectives and foci: supported housing as a "critical component of effective community support," the principles (including inclusion of the "most disabled") and movement from a continuum model, consumer "voices" and "preferences," examples of supported housing (e.g., "assertive community treatment", collaborative approaches with volunteers), the relationship with independent living and residential treatment, and systems design.

In the opening articles of the special issue, supported housing is decribed as part of a "paradigm shift" which "embraces a vision of people with severe mental disorders succeeding in the community living situation of their choice through access to flexible, individualized services and supports." Elements of the paradigm shift include: housing instead of residential treatment settings as a sole mode of delivery and development of normal housing; choice of a home not placement; roles of community member, tenant and householder rather than client; shift in "locus of control" from staff to client; social integration versus disablity grouping; learning in "permanent settings" rather than transitional; individualized and flexible supports; and "most facilitative environment and best functioning."

Analysis:

The articles create a picture of supported housing as a developing multi-dimensional concept which has very different meanings and interpretations at the "consumer," service, practice, philosophical and policy levels. While one of the strengths of the approach is its emphasis on choice, the articles indicate that the new approach encompasses many of the same dimensions and assumptions as previous models. These include professional approaches with casemanagement and ways of thinking about systems integration. Important distinctions are made in the articles between residential "treatment" and supported housing, the failure of the "continuum" model in part due to inadequate resources for independent living, teaching skills and "providing support," and its role in moving toward regular housing and promoting community membership. Efforts are made to include the empowerment and autonomy dimensions

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[46] *Also, see special journal issues on serving persons with "dual disorder" of mental illness and substance abuse (1991), supported education (1993), clubhouses (1992), community support system (1989), psychosocial rehabilitation and mental illness (1990).*

and people who are "the most disabled." Supported housing primarily focuses on adults and families, and children and youth are not as directly considered.

Contribution to Conceptual Model:

Supported housing explicitly includes in its umbrella regular housing with support services of choice for people with "severe mental illness" (with 1995 research shifting to consumer-preferences in housing, see Psychiatric Services). To that extent, models of personal assistance services which are to be available on a 24 hour basis in people's own apartments or homes parallels these dimensions. However, the concepts of individualized and flexible supports, does not necessarily imply user-direction of the services. As a more newly defined area, opportunities exist to promote greater "client control," in people's "own homes." The articles also offer specific suggestions regarding assistance such as: apartment search assistance, help in moving, money management, structuring time and leisure activities, medication management, and crisis support.

Keywords: *supported housing, mental health, independent living, community services, community support, housing, self-determination; autonomy; community membership*

Citation: *Mancuso, L. (1990). Reasonable accommodations for workers with psychiatric disabilities*[46]. **Psychosocial Rehabilitation Journal**, *14(2), 3-19.*

Summary:

The article is one of a growing number applicable to the implementation and evaluation of the Americans with Disabilities Act (ADA) in the employment of people with psychiatric disabilities. Describing the "right to employment" as a symbol of full citizenship, the author highlights the high unemployment rate (85%) among people with severe psychiatric disabilities (Anthony & Blanche, 1987), lists functional limitations (e.g., screening out environmental stimuli), reviews the history of accommodations in the workplace, the definitions and legal basis for reasonable accommodations, and implementation of reasonable accommodations.

Analysis:

The article is one of the better presentations of the concepts underlying the hiring and inclusion of adults who happen to have a psychiatric disability in the business sector. Its strengths lie in its framing of the right to employment, inclusive of people with severe psychiatric disabilities, and its targeting of the central concepts which have been often misunderstood by the employment sector and people with disabilities: reasonable accommodations and qualified applicants and employees.

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[46] *Also see, Mancuso, L. (1993, June). Case studies on reasonable accommodations for workers with psychiatric disabilities. Sacramento, CA: California Department of Mental Health.*

The article ends with a call for advocacy to reverse the trend for people with psychiatric disabilities to adjust to the workplace, and instead have the workplace accommodate the person. The framework for reasonable accommodation, and actually the law itself, is based upon these individual adjustments, and are not framed as part of the creation of workplaces which as a matter of course "accommodates" employees (e.g., regular employees with options of flexible scheduling, shared job options) as a benefit to the productivity of the workplace as well as the employee.

Contribution to Conceptual Model:

For purposes of the development of PAS the author describes accommodation in terms of modifications to the physical environment, job modifications, schedule modifications, and changes in interpersonal communication with "job coaches" playing the creative development role. The relationship of personal assistants, the roles they may play, and the role of the employee in proposing accommodations are not discussed, and the author frames supports (as identified through psychiatric rehabilitation) as primarily designed to compensate for the individual needs of employees with disabilities.

***Keywords:** employment, psychiatric disabilities, accommodations, Americans with Disabilities Act, employment supports, personal assistance services, psychiatric rehabilitation*

***Citation:** Lorion, R. & Allen, R. (1989). Preventive services in mental health (403-432). In D. Rochefort (Ed), Handbook on mental health policy in the United States.[47] Westport, Ct: Greenwood Press.*

Although the prevention of emotional and behavioral disorders was being conceptualized a decade ago, substantial evidence of its programmatic feasability and viability did not exist. Since the efforts of Carter's Commission on Mental Health (1978) and the establishment of the Alcohol, Drug Abuse and Mental Health Administration (1983), the "idea of prevention has become the impetus behind a major national movement."

The chapter describes positive prevention outcomes, two taxonomies for prevention "interventions" in mental health services: public health (primary, secondary - e.g., early interventions, and tertiary preventions); and a "universal" prevention model with a recipient focus instead of intended outcome focus). Exemplary preventive interventions are highlighted in adolescent pregnancy, reducing the risk of developmental delay in children from high-risk families, and prevention of substance abuse.

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[47] *See also, prevention in the field of developmental disabilities, for example, Allen C. Crocker (1992). Data collection for the evaluation of mental retardation prevention activities: The fateful forty three. Mental Retardation, 303-317 (particularly children with a "medical home" and "presence of family support" as childhood concerns; use of family life curricula as a service indicator; and out-of-home placements as risk indicator).*

The article concludes with policy and program issues (on how to change the "developmental course" of children born to high-risk families or vulnerable to high-risk activities):

** Funding and reimbursement (children as a minority group; need for evaluations of existing prevention programs, commitment to prevention by Community Mental Health Centers; treatment and prevention practitioners as competitors);*
** Identifying target populations (prevention programs as "community-wide, high-risk programs, focus on populations rather than events, overidentification of people at-risk and the use of multiple risk criteria);*
** Risk assessment (concept in epidemiology, allowing for "efficient use of program resources," predisposing or modifiable risk factors, micro and macrolevel service interventions, precipitating risk factors and life events)*
** Prevention advocacy and social reform (e.g., home vs. school-based sex education).*

Analysis:

The article frames prevention in the context of either public health (predisease, individual intervention models) or as community or universal preventions based upon the public media and social skills. The major proposed outcome is the reduction of the "rate of the disorders," in contrast to broader range of positive life outcomes. The "exemplary" programs are based upon the incorporation of social program applications (e.g., "cognitive behavioral approach to teen pregnancies" through a pregnancy prevention curriculum, peer teaching to reduce social pressures to smoke) which appear too limited to affect the social issues they are designed to address. The authors appropriately note that there is sometimes "confusion on what is to be prevented" and invalid assumptions about who is at-risk. The evaluation methodologies, which include scores on problem solving tests, are not necessarily suited to the social applications in the programs. All the program and policy recommendations are arguably flawed.

Contributions to the Conceptual Model:

Prevention could be a viable framework for "service system" forms of personal assistance services (PAS) or for thinking about PAS in the context of health care. However, within these contexts, it would be necessary to examine and reframe the basic assumptions (e.g., "what is at-risk and what is to be prevented"), definition or prevention, outcomes of prevention, "innovative programs," evaluative approaches, and the frameworks for understanding social (public) policy and its practice.

***Keywords:** mental health, health prevention, risk, health promotion, service intervention, public health policy, adolescence, at-risk youth*

TOWARD PERSONAL ASSISTANCE SERVICES IN THE FIELD OF TECHNOLOGY ASSISTANCE/DEPENDENCE

Children, and youth with medical needs, who may use technology, have often used in-homes services, sometimes as part of family support. However, such options have been less accessible for adults (See, also, Racino, 1988), particularly to live in their own homes, or as youth models of assistance. This section is organized around several articles which contribute to and overlap with other sections (e.g., brain injury and medical needs):

- a literature review of health needs and outcomes of persons with mental retardation;
- an article on an autonomy, adolescent hospital to community transition project;
- a focus group article on parents' perspectives on medically complex children; and
- an interview study of parent and provider perspectives on the American Indian health care delivery system in New Mexico.

Citation: Hayden, M. & DePaepe, P. (1991). Medical conditions, level of care needs and health-related outcomes of persons with mental retardation: A review. Journal of the Association of Persons with Severe Handicaps, 16(4), 188-206.

Summary:

This article summarizes the results of a literature review conducted at the University of Minnesota to "analyze existing data on health needs of people with mental retardation and possible barriers to integration in the community." Based on structured review process, the authors identified 47 studies and reports which met their criteria for inclusion. The authors provide a detailed review of the methodological limitations and findings of these studies based primarily on a study by study overview in the areas of medical conditions, level of care, and health related outcomes.

Four main categories of necessary services and supports were: direct medical services, ancillary medical services, additional support services, and family/community supports. The primary categories of barriers were: financial disincentives and lack of residential options; funding for in-home medical and support options and actual payment of medical care and services; inadequate community medical care, training and services; and unavailability or inaccessibility of medical care and services as a result of geographical location. Recommendations include increasing resources, additional training and education for medical personnel, improved interdisciplinary and interagency coordination, and the need for ongoing monitoring.

The authors conclude that while unequivocal conclusions cannot be drawn given the methodological weaknesses in existing studies, the literature review reflects the fact that it is possible to meet the medical needs of people with mental retardation in community settings, but the service delivery system has room to make improvements. In their final discussion, the authors recommend revisions in the Medicaid system, curriculum in medical schools, more useful *evaluation research in delivery of medical services, and the need to view good health care as a medical not a residential issue.*

Analysis:

An excellent journal review summary, the article highlights the growing consensus of community supports for people with medical needs as viable options. In relationship to the identification of service needs, the summaries, however, offer relatively little discussion of services across environments (e.g., work, school), does not describe emerging approaches for adults in community living, and does not frame in-home services within the context of the family support movements. Significantly, the authors did emphasize a number of important findings, for example, that the "need for rapid access to medical care or 24 hr medical care" was needed by only a small number of individuals, and that disincentives continue to exist to generic access to health care.

Contribution to Conceptual Model:

Several identified development issues with PAS are: (1) utilization of same services as the general population with only a relatively small need for specialized medical (as differentiated from disability health) services; (2) the continued concentration on casemanagement and coordination, and group or foster homes as primary residential service types with inadequate attention to health needs in other environments; (3) the need for Medicaid (health care financing) reform to increase service accessibility; and (4) the delineation of specific types of family and community supports (e.g., home modifications, health care aides), including respite.

Keywords: *community-based, community integration, community services, developmental disabilities, health care, service delivery, health-related outcomes, deinstitutionalization, health care financing, medical needs*

Citation: *Hostler, S., Gressard, R., Hassler, C. & Linden, P. (1989). Adolescent autonomy project: Transition skills for adolescents with a physical disability.* ***Childrens' Health Care****, Vol. 18(1), 12-18.*

Summary:

The article describes an effort by a rehabilitation center ("specialty hospital"), in conjunction with a local "Independence Resource Center" to develop an intervention program for early adolescents (11-14 years old) with physical disabilities "to promote autonomous functioning." The interventions consisted of the adolescent "interpretive interview," a physical exam, individual and group health education, social skill training (assertiveness training, peer group activities, adolescent apartment for life skills, newsletter and group meetings) and interaction with adults from the independent living center. The goals of the adolescent intervention included: (a) understanding one's diagnosis and being able to communicate that understanding to others; (b) health and wellness education; (c) advocacy and responsibility for *health care; and (d) realistic future planning with activities carried out by professional program staff.*

The adolescents were interviewed pre- and post-intervention using a structured interview of 94 items to assess the adolescent's knowledge about diagnoses and disability, understanding of treatment plan, interaction with health care professionals, sexual knowledge and sexual education experiences, self-care skills, attitude about autonomy (E.g., It's okay for me to stay home by myself.), independence and responsibility, socialization and future plans (E.g., Do you plan to get married? Do you think you'll be a parent someday?).

The article concludes with a discussion on adolescence and findings (e.g., an increase in the number of adolescents who thought they were able to have children; need to increase the number of sexual education experiences for adolescents; an increase in adolescents who performed household chores (linked with self-esteem), and an increase in shopping with family and friends (i.e., mastery in activities outside the home)).

Analysis:

The article attempts to integrate the concepts of adolescent autonomy, family-centered care, rehabilitation interventions, and adolescent interviews in describing an Adolescent Autonomy Project. From the perspective of conceptualization and research, it would have been helpful if the authors included a results section on the interviews.

As one of the few articles where adolescents are asked their perspectives, the questions include potentially controversial areas such as sexuality. The intervention (skill training) activities remain as common practice strategies, including assertiveness training, peer activities, and transitional apartments on hospital or institutional grounds (and in the community) not only for youth with physical disabilities, but for other groups as well (e.g., mental health, brain injury, mental retardation).

Contribution to Conceptual Model:

The concept of "transitional services" (and transitional apartments) continues to be popular form of service provision supported by proponents in the independent living movement, the community integration movement, and the rehabilitation, medical and education fields. However, this service model has tended to exclude people with significant disabilities who may require 24 hour assistance from the use of personal assistance services (PAS) in their own homes and as part of community life. The areas of sexuality and parenting, and peer activities are also ones to be explicitly addressed in the PAS models.

***Keywords:** transitional services, adolescent health, personal autonomy, family-centered care, service interventions, physical disabilities, sexuality, adolescence, physical disabilities*

Citation:** Diehl, S.,, Moffitt, K. & Wade, S. (1991). Focus group interview with parents of children with medically complex needs: An intimate look at their perceptions and feelings*[48]*.* ***Childrens' Health Care*, Vol 20(3), 150-161.*

Summary:

The article reports on focus groups with parents of children with medically complex needs in order to identify what they perceived to be their primary needs and those of their families. The methodology included small focus groups of 6-10 parents (98 participants total), with trained moderators and assistants, audiotaped and coded data, and a combination of ethnographic and content analysis. The primary findings were reported according to the most frequently held opinions and quotes from the participants in each of these categories:

Family issues (acceptance of the child with a disability, lack of ability to function spontaneously as a family unit, sibling jealousy, lack of respite care and helpfulness of support groups);
Illness specific information ("as it applies specifically to their child" and timing of information); equipment, and training in its use (e.g., how the machines function, what alarms actually mean, back up system information, especially for suctioning techniques, preparation for problems that might arise such as pulling out tube);
Financial assistance (e.g., middle income famlies not qualifying for aid);
Casemanagement/knowledge related to professionals; educational mainstreaming and placement issues;
Medication and pain management (need to know information and be listened to);
Hospitalization;
Daily physical needs (like feeding schedules, stimulating oral development, safely transport children);
Child's emotional and communication needs (e.g, parents as interpreters); and growth and development; and
Death and dying (e.g., someone to talk with about the subject).

The authors conclude with a discussion, including themes such as the lack of knowledge of home care, planning for the future, and the fragmentation of training, needs and services.

Analysis:

This article was an example of a focus group report, used as a way of obtaining information about personal life experiences and service perspectives. However, like most of the reported groups, one of the strengths of the methodology - to better understand how and why

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[48] *See also, other policy based articles, such as health care-child welfare partnerships on transitioning medically complex children in the community (1989).*

participants[49]. The findings detail areas which began to frame issues from a parental perspective and offer the possibility of addressing areas which might otherwise be neglected in PAS designs (e.g., death and dying: "nobody wants to talk about it.")

Contribution to Conceptual Model:

As young children with medical needs and their families face in many cases the necessity for paid assistance, PAS (in contrast to home care) needs to be designed from the perspective of the families (inclusive of their children with medical needs). The perception still exists that children with complex medical needs require out-of-home residential settings (e.g., small group homes) and support services have not yet been viewed in some places in the country as a viable option.

***Keywords:** focus groups, parents/families, health care, home care, childrens' health, medical needs, family-centered care*

***Citation:** Malach, R.S., & Segel, N. (1990). Perspectives on health care delivery systems for American Indian families. **Childrens' Health Care**, 19(4), 219-233.*

Summary:

In the context of national health care reform for special needs children (e.g., PL 99-457), the article reports on a study of 112 non-Indian and Indian service providers and parents (of children ages 6 months to 30 years) in New Mexico from the pueblos, Apache and Navajo tribes. The survey was developed by a team of Indian parents with special needs children and non-Indian parents, and the responses from the face-to-face interviews were coded (35 categories) and then grouped into seven categories (e.g., family financial resources, support for families). Little difference was seen between pattern of responses between parents who were service providers and those who were not.

The article identifies factors prohibiting (e.g., agency policies and procedures, ineffective communication, lack of community-based services) and facilitating use of health care services (e.g., transportation, community-based services, accessible information on services, case management, advocacy with differential responses between parents and providers on emotional support and respect, and interpreters). The authors reported that families and service providers had similar ideas for generating possible strategies for improving services and understanding (e.g., effective communication, availability of an interpreter). The authors also conclude that many of the factors which enhance access to health care services apply whether Indian families obtain those services privately or within the Indian Health Services (IHS).

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[49] See, for example, World Institute on Disability focus group on personal assistance services, November 1994 which was designed to achieve consensus.

The discussion identified four types of communication obstacles with suggestions for each: us of interpreters, change in professional language and employment of parent-parent liaisons or educators; training of health care providers in non-verbal cultural communication styles (use of silence in conversation); and use of non-traditional communication aides ("within Indian cultures, Indian healers ask few questions and do not use forms").

Analysis:

One of the article's best contributions is in eliciting the perspectives of Indian parents, which remains a less common approach than might be expected. Significantly, the authors distinguish between kinds of support and service availability, between private and IHS services, and use a broad definition of "Indian parent" to encompass extended family members. However, the authors do not distinguish between parents with young or adult children living at home (and do not interview the "children"), and frame their findings regarding the similarities and differences between parents who were service providers and those who were not (and service providers alone) in ways which appear to blur potentially significant issues.

Contribution to Conceptual Model:

The article was included here primarily as an example of service and support research which is designed with and elicits the perspectives of culturally diverse groups (in this case, American Indians) as part of the "model" development process. The study also distinguished between "agency" and "family" financial resources (which is significant in voucher-reimbursement models), how people view who is responsible (significant in the systems design), information access (for PAS, significant for people who are excluded from this information, such as children with cognitive disabilities), and concrete suggestions for overcoming communication obstacles (e.g., interpreters).

***Keywords:** American Indians, health care, health care delivery systems, community services, case management, (family) support, communication, financing*

TOWARD PERSONAL ASSISTANCE SERVICES YOUTH WITH DISABILITIES

Youth approaches to personal assistance services (PAS), have at times, been incorporated in family support. User-directed approaches, intergenerational mentoring, and youth-to-youth options hold particular promise, within the ocntext of changes in the organizations and institutions interacting with youth, and across all aspects of youth lifestyles (Racino, in press, 1996).

This section is organized around:
** an article in a role model series in Exceptional Parent;*
** an article on youth development and its relationship with health and education services and policies, communities, and cognitive and social development;*
** an article on the Americans with Disabilities Act and how it applies to children written for parents;*
** an article on innovative programs and policies for youth-at-risk (communities, leadership);*
** an article on play, a theme missing in much of the adult literature;*
** an article on autonomy in adolescence (combining family theory with acceptance and decisionmaking by youth);*
** an article on family supports in rehabilitation across diverse disability groups;*
** an article on confidentiality issues with minors;*
** an article on transition from child-centered to adult health care for adolescents with chronic conditions;*
** a qualitative research study of personal assistance services in Japan;*
** a national survey of best practices in self advocacy and empowerment;*
** a national survey study of seven public agencies in each state on youth with chronic illnesses and disabilities;*
** an international perspective (essay) on social and family structures, and youth movements (e.g. mentoring).*

***Citation:** Cargnel, S. (1994. May). Becoming a contender: All you need are practice and determination. Exceptional Parent[50], Vol. 24 (5), 28-31.*

Summary:

The essay, written by a 16 year old sophomore in New Jersey, describes his turning experiences with "wheelchair" sports. He recounted how his classmates treated him ("my classmates constantly reminded me of what I could not do"), of how he had nothing to do after school, and how he had no one to play sports with ("it was obvious that I couldn't participate

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[50] Exceptional Parent started a new 1994 series on role models as a regular feature; see, Harvard student athlete talks about growing up deaf (Carrie Miller) and a disability advocate and presidential appointee talks about her experiences growing up (Judy Heumann).

in "normal" sports like football or Little League"). His mother came up with the answer - a wheelchair track and field team at the Childrens' Specialized Hospital. Using a wheelchair for the first time in his life, he "took things as they came," qualified for the Nationals the first season, and for the first time "felt accepted for who I was." The essay describes his experiences becoming a leader at 14, a person who could compete, believed in himself, and could hold his own. He also started wheelchair basketball, with the "challenge of playing with adults as a kid," making him a better player. Stefano ends with crediting sports with the fact he now "has the nerve to ask a girl out on a date" and that it was "an essential stepping stone in life."

Analysis:

The perspectives of youth with disabilities still are not often shared, and this series of articles is significant in that way. Besides his poignant perspectives (his story) as a teenager, the article also makes several points relevant to PAS development: (1) what people want is often framed in relationship to current constraints, limited choices and available options; (2) students' experiences with classmates can compound the situation, causing other adults to become involved; (3) he came to define himself as a leader, in part due to being the "oldest person" on the team, who could compete, believed in himself and could hold his own; (4) participating in sports led to friendships, new activities, and confidence; and (5) no particular assistance other than coaching was described, though both were "funded" teams (which could mean that the team or place had funds for additional support services).

Contribution to Conceptual Model:

Most of the service models of PAS tend to be stilted and not recognize the nature of play, love and the relationships people have with each other (sometimes, to the point of not allowing these to be "fundable" support services). Financing for recreation also has tended to be part of disability activities programs, and the money has often not been released to be either directly used by people themselves (in ways they might want) or by community recreation places (though now allowable in areas such as family support services).

Also, the article illustrates how people come to see themselves in relationship to their environment, (E.g., as a contender, as a leader, or as unable to be part of "normal" sports). To the extent that efforts toward PAS contribute to environmental change, what people want and how people live also may change.

Keywords: *sports/athletics, schools, youth leadership, disability (spina bifida), personal assistance services, recreation, (community) financing, social acceptance, attitudes*

Citation: *Nosek, M. (1989). "Consumer responses to personal assistance options (27-29)". **Personal assistance services in Japan: Effect of productivity and daily living among Japanese with severe physical disability**. Houston, Texas: Baylor College of Medicine.*

Summary:

"This study used a combination of empirical and observational techniques to examine the use of personal assistance by a sample of Japanese adults with severe physical disabilities, and how their use of personal assistance is related to their level of productivity. Thirty individuals from the Tokyo and Kansai (Osaka, Kyoto, Nara) areas were given a written questionnaire, which include the author's PAS Index and the DeJong Productivity Scale; 15 people were personally interviewed."

Beginning with independence as a prominent goal for people with disabilities, the paper describes the scarcity of personal assistance services in America and Japan, the study methodology and findings, the author's experiences in Japan, and consumer responses to personal assistance services. The author specifically highlights the two findings that (1) "those who lived alone with non-family assistants had the highest level of satisfaction and those who lived with family but had non-family assistants had the highest level of productivity," and (2) "Individuals who were among the most productive also tend to be married, older and had less education." The author also describes "anecdotal data" on the desire for "control" of pas, the desire for independence from families as providers, the needs for funds and availability of assistants, and the removal societal barriers to productivity[51]*.*

Analysis:

Each of the paper's sections are strong in their own way; however, the paper was selected for inclusion for the section on "consumer responses" which describes issues also common in the USA: parents as assistants, volunteers as assistants, and the use of paid assistance. First, the feelings of dependence and resentment that people with disabilities may have when they are "forced" to rely on family for assistance, particularly at a work site. Second, the need for a sense of hopefulness about societal opportunities in order for youth to take responsibility for their own lives, and for parents to focus not only on services and care ("environmental barriers"). Third, lack of the concept of the person with a disability as an employer of the assistant (and also a "friend"), and its contrast with assistance which is part of the natural environment (e.g., "challenge at hand is how to have control without exchanging money") and assistance which is as available "as air."

Contribution to Conceptual Model:

Each of the sections of the report is a new contribution to the research and/or technical/personal knowledge base about PAS. In particular, the findings on productivity are critical in a political environment where pas is framed in the context of the employment and contribution of people with disabilities in society (e.g., cost-effectiveness of pas).

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[51] *See, also critiques of productivity as standard, including effect on lives of people with significant disabilities (E.g., Ferguson & Ferguson, 1989)*

The section on the life situation of persons with disabilities in Japan also presents a similar framework for understanding the "context into which personal assistance relationships are built": medical care, technology, housing, environmental accessibility, transportation, education, employment, pension and advocacy. The areas raised by the consumers are particularly critical in light of current public policy movements in the US, including policies which do not promote environmental and societal change (e.g., the separation of disability policy from regular economic and social policies), and the growing family support efforts which can also be designed in ways which support dependency (e.g., on the part of adult children).

Keywords: *societal (environmental) change; personal assistance services; (physical) disabilities; families; personal autonomy; employment and productivity; community services; independence; health care; independent living*

Citation: *Moreillon, J. (1992). Young people's perceptions of health and health care.* ***Journal of Adolescent Health Care****, 13, 420-430.*

Summary:

The conference paper briefly highlights the evolution of social and family structures (e.g., trends in individualism and "communitarian" values, women in the labor market, roles of families and schools), the roles of families during the transitional period of adolescence (social changes affecting families; democratic vs autocratic modes of decisionmaking, increasing youth autonomy and parental conduct rules), and how "youth movements help adolescents in their transition to adult life" ("mentors"; adult contributions to healthy youth; family dynamics, inclusive of parental control).

Analysis:

The paper was initially selected for inclusion as presentation of youth perceptions' on health and on how "youth movements" such as the Scouts contribute to transition to adult life. However, the paper comes from a professional perspective, with its major contribution to PAS development the discussion on the mentoring relationships. This includes guidance in character and competency development with a bond of affection and loyalty between the two people which are located "in and out of the family" and can also be a means of transmitting "skills and values." This essay also touches on "parental control," family decision-making structures, effective parenting, and family structural changes.

Contribution to Conceptual Model:

Mentoring relationships, when thought about in a framework of paid and unpaid assistance, are a form of reversal of PAS employer-employee models as conceptualized for adults with disabilities, and have already been translated into "mentoring" human service programs in fields like mental health. However, mentoring relationships with youth are worth exploring further to the extent they can be developed within regular environments, and are based upon a *foundation of mutual respect and assistance, and are one option among others.*

Keywords: *adolescents, health care, health (development), adult mentors, family, transition, adulthood, public policy*

Citation: *Jackson, A., Felner, R., Millstein, S., Pittner, K. & Selden, R. (1993). Adolescent development and educational policy: Strengths and weaknesses in the knowledge base.* ***Journal of Adolescent Health****, 14, 172-189.*

Summary:

The article reports on the panelist discussions of the Carnegie Corporation's Turning Points: Preparing American Youth for the 21st Century (released in June 1989). Jackson's section highlights the report's recommendations on the "linkage between the education and health of adolescents"; Felner's on the mismatch between the conditions and practices in schools and the needs of young adolescents; Selden's on reforms in assessment in relationship to "adolescents' cognitive and social development"; Millstein's on adolescent health promotion (e.g., use of school-based clinics, interdisciplinary training programs nationwide, linkage health education, services and policies); and Pittman's on the conceptualization of a new paradigm for youth development (e.g., Youth development is "not a program", but a "process in which youth are engaged.")

Analysis:

The conceptualization(s) of youth development and the ways in which services and programs, public policies, and communities and community organizations are discussed offer a useful framework for public policies of youth with and without disabilities. The dis-tinctions between youth development and youth programs, and the integration of the health, education, and the community sectors are critical starting points on PAS.

In particular, the authors point out (1) the lack of overall responsibility in the U.S. ("no professional, no organization, no institution, no planning body") for youth development;" (2) the need for changes in "all institutions interacting with youth, not just health and education sectors, but also community youth-serving agencies, religious organizations, private industry and the research community"; (3) a move away from schools as comprehensive service agencies (also, see opposite developments in special education); (4) need for a "fundamental shift in the way innovation and practice are assessed; (5) the use of school-based clinics as a health model; and (6) the undervaluing and underfunding of the organizations ("civic, religious, recreational, informal education, community service organization, and parks and recreation, libraries, museums") that are "assisting families with the socialization and development of children and youth."

Contribution to Conceptual Model:

For PAS, the youth development framework is probably the most critical, together with the way(s) in which personal, organizational and societal responsibilities are framed. Specifically, on the level of "program" strategies, pas should not be incorporated within the school-based clinic[52] framework; early developments of PAS need to be aimed toward future changes in assessments (without which it will come to mirror existing community service models); and PAS within the context of schools and communities needs to support a shift toward communities and away from schools as "comprehensive service centers."

Keywords: *educational policy, adolescent development, middle-grade schools, Turning Points, youth, community organizations, children at-risk, health reform, school-based clinics*

Citation: *Chaikind, S. (1992). Children and the ADA: The promise of tomorrow.* ***Exceptional Parent****, 22(2), M8-M10.*

Summary:

The article "summarizes the important provisions of the law (the 1990 Americans with Disabilities Act) in light of how they might affect children." Viewed by the author as the "missing link" in the compendium of laws on the civil rights of children, the ADA potentially has its greatest impact in creating "hope" for the future ("that childrens' early aspirations are attainable and unlimited.")

Detailing the employment provisions of Title I (including compensation when individuals are wronged), the authors note the importance of children knowing that their career will not be impeded by "small things unrelated to their skills," which employers can accommodate. Telecommunications is described as enabling children to "make that telephone call to Grandma whenever they want to;" physical accessibility as enabling children "to go down the aisle of the toy store to pick out their own toys" and for teenagers to "share a movie or hang out with friends." Transpor-tation accessibility means "college students can come home for the weekend with less trepidation."

The article also notes that the accessibility governing regulations went into effect on January 1992 with small businesses having more time to comply, and gives advice on obtaining information related to compliance. Stating that shopkeepers and businesses can benefit, the promise for children is that "they know they are several steps closer to equality - a benefit that may be priceless."

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[52] *Articles on school-based clinics appear during this review period in the Journal of Adolescent Health.*

Analysis:

At the practice, legal and educational levels, many of the issues faced by employers, businesses, colleges and universities reflect the same ones that were to be addressed by the Rehabilitation Act of 1973. The interpretation of the provisions for children, in the context of future hope, is significant and "down to earth;" however, the integration of the compliance and regulatory perspectives without a context for how the ADA translates into community changes (other than law and enforcement) creates two dichotomous views about what people are trying to achieve. The parents are given the message that these places will create these changes or if they do not follow the law, a person as an individual can pursue legal remedies.

Contribution to Conceptual Models:

In relationship to PAS, the article is effective in its political and practical presentation of how the law (ADA) actually translates into daily life. To the same extent, PAS also can be presented as part of the natural rhythm of people's lives, varying by age in the pictures it creates. Some of the public images of PAS tend to be associated with a costly service, and with something associated with "special" services and "special" people, and unrelated to the general public (and how people live).

Keywords: *accommodations, Americans with Disabilities Act, children, communities, public policy, civil rights, accessibility, employment, education, telecommunications*

Citation: *Dryfoos, J. (1991). Adolescents at risk: A summation of work in the field: Programs and policies. Journal of Adolescent Health Care, 12, 630-637.*

Summary:

The article summarizes the results of a review of 100 diverse "successful" programs in four categories of prevention (substance abuse, delinquency, teen pregnancy, and school failure and dropout) which "appear to have potential for changing high risk behavior." The two major themes were the need for individual attention ("empowering caring adults to take the responsibility for giving support and acting as an advocate for one or more of the high risk children") and the importance of communitywide, multicomponent interventions (i.e., configurations and collaborative arrangements which involve schools, public and private agencies, parent groups, media, police, clergy, businesses, universities and youth). It was also significant that in the study of multiagency efforts, school buildings were often the sites and "that (these efforts) are operated and funded by agencies outside the school system."

Common components of successful programs that "could document behavioral changes" were early intervention, basic skills (e.g. achievement levels), healthy school climate (school teams, teacher roles, alternative schools), parent involvement, peer involvement (giving "real" responsibilities), connection to the world of work, social and life skills training (improved competency, decision-making and assertiveness skills), and attention to staff training and *supervision (including credit to charismatic individuals). The author describes "what doesn't work" including her bias against "self-esteem" programs ("bandaids"), the lack of research on peer counseling and efforts to simply invite parents to attend workshops.*

The author concludes with policy implications for the "one in four children in the United States" who are at-risk of "maturing into responsible adulthood" with a priority on the "most troubled communities." The article supports new institutional forms of the community schools as the centerpiece, in conjunction with reform in health and social services, including significant changes in state bureaucracies. Highlighting "comprehensive" programs and youth initiatives, the article calls for leadership for a "children's crusade" that "will ensure every child both a good quality education and all the support services needed to benefit from the schooling."

Analysis:

The article is an excellent one in drawing attention to several significant developments which are continuing to affect the lives of children, adolescents and adults with disabilities. These include: (a) the movement toward schools as the centerpiece with the community and community life revolving around it (see parallel services integration in field of special education); (b) the contrast between the movements toward supporting (quality life of) families, and the interventions for at-risk children when the family is said to become "dysfunctional" (a matter of significant public policy concern); and (c) the framing of innovations in programs (and individual change) in the context of community, bureaucratic or systemic reform.

Contribution to Conceptual Models:

The article was particularly included here because many of the "common components" of programs, correspond with ways in which paid assistance in disability are translated into social programs (e.g., social and life skills training), yet the context of schools appears to be broader and less stigmatizing. Each of the areas mentioned above (e.g., connections to the world of work) also are essential to address, both at the person level, and if any significant "integrated systems"[53] *approaches at the state and federal levels are to occur.*

Keywords: *adolescents, innovations, schools, community organizations, at-risk youth, (adolescent) health care, prevention, public policy, financing*

Citation: *National Center for Youth with Disabilities. (1993, Winter).* ***Teenagers at risk: A national perspective of state level services for adolescents with chronic illness and disability***[54].

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[53] *Also see the General Accounting Office (GAO) report on integrated service systems (1991).*

[54] *See also, series of literature (CYDLINE) reviews on youth with disabilities, self-esteem for adolescents with chronic illnesses and disabilities (1993), recreation and leisure (1992), race and ethnicity (1991), promoting decisionmaking skills (1990), transition from pediatric to adult health*

Minneapolis, MN: Author.

Summary:

The paper describes the results of a survey conducted in late 1990 and early 1991 of the directors of seven public agencies in each of the 50 states and the District of Columbia. These included in each state: Maternal and Child Health, Children with Special Health Care Needs, Adolescent Health Coordinators, Departments of Special Education, Mental Retardation/Developmental Disabilities Programs, Developmental Disabilities Councils and Vocational Rehabilitation Services.

The "most overwhelming" finding was that adolescents were not considered to be a priority either for programming or for funding, with infants and toddlers through the age of two receiving the greatest programming attention (85%). It was also clear that lack of information and awareness across (state) level agencies was the norm, not the exception, of agencies and programs[55]*.*

The report describes the services available to adolescents (E.g., home health services, family supports), the programs (E.g., 100% of state vr agencies offer career planning), who should provide the services (E.g., the Department of Education as "catch all" when services do not fall under another agency's responsibility), the major issues (E.g., transition to adulthood, "hidden disability" and employment), and future research, legislation, policy and program development (E.g., integration of service delivery systems; support services, such as casemanagement, transportation, school-based health programs, independent living assistance and respite care).

The major recommendations revolve around states placing attention on the "total needs of youth with disabilities" (E.g., the health of a young person related to his or her career and educational choices); the activities of the state agencies; federal task forces of interagency directors; federal legislative mandate for increased priority and resources directed to youth with chronic and disabling conditions; federally mandated interagency collaboration at the state level; and state focal point for youth coordination.

Analysis:

The paper provides an excellent framework on presenting the major issues facing the

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care (1993, 1994) from this Center.

[55] *Also see as an example, the Office of Technology Assessment - The role of federal agencies. Journal of Adolescent Health (1992), 13, 183-235 and Dougherty, D. (1993). Major policy options for a report to Congress on adolescent health. Journal of Adolescent Health, 14, 499-504.*

people (state directors and their staff) who work for agencies serving adolescents, the organizations and services offerred and desired by the directors of the systems which provide these services, and a picture of the systemic issues of the future. The organizations surveyed, however, do not provide a comprehensive view of the lives of adolescents, particularly in relationship to specific disability areas and to non-service related governmental functions.

In relationship to PAS, the report discusses related services (e.g., home health services, self advocacy training) and related factors (e.g., inadequate community living options, health care financing). However, it does not intend to present issues from a service user perspective or to highlight or discuss home health services. Mental retardation/developmental disabilities and secondarily "independent living" were given greater weight than mental health and brain injury. It is significant given a call for national legislation on PAS and movement toward national health care reform, that the report chose not to frame the policy and legislative recommendations within this context.

Contribution to Conceptual Models:

Significantly, this paper explicitly distinguishes between systems (MCH Programs, CSHCN) and services in ways that clearly delineate "state" level entry points for further development of PAS. The paper also frames issues of adolescents (with disabilities) as a "forgotten population" which has significant implications for future collaborative change endeavors for (personal assistance) service (and community) development.

Keywords: *legislation, policy, integrated service systems, adolescents, chronic disability, interagency coordination, transition, health care, education, (vocational) rehabilitation childrens' health, mental retardation/developmental disabilities*

Citation: *Kelley, S. & Lambert, S. (1992). Family support in rehabilitation: A review of research, 1980-1990.* ***Rehabilitation Counseling Bulletin****, Vol. 36(2), 98-119.*

Summary:

The article reviews 30 published studies (observational. surveys, case studies, randomized controlled aimed at improving support-outcome relationships) on family support in rehabilitation across "broad disability categories" from an initial sample of 13,000 publications. It provides an overview of trends and factors in "family involvement in rehabilitation" (e.g., conflicts between client and family self interest) followed by a discussion on the conceptualization and measurement of "social support."

The results are presented according to four categorical disability types (e.g., mental illness, developmental disabilities, chronic illness and physical disability, substance abuse disorders). The article ends with the identification of "serious problems" in the empirical literature together with recommendations regarding the integration of family-centered services with client rehabilitation and the necessity for effective support to depend on the specific person-

situation.

Analysis:

Studies of family subsidies and families-at-risk did not appear to be included. The findings most relevant for these analyses were: the low correlation between support provided by others and the individual's perception of that support (Sarason, Sarason, & Pierce, 1990), family support factors and the link with "treatment compliance" (with family members as a way to achieve greater cooperation by the individual), requesting information as a coping strategy, strongly coordinated family relationships (and energy on the "management of the disability") as having potentially adverse consequences on the individual, families as the expected primary caregivers after hospitalization for mental illness (incorporating families into interventions), families as "adjunctive resources" in employment, and parental stress caused by "taxed financial resources, requirements of physical care, and social isolation."

Contribution to Conceptual Model:

The involvement of family members, without individual consent, remains a problematic area in provider support and service, with further abridgement occurring through guardianship arrangements. In relationship to PAS, youth approaches also rely on a conceptualization of the nature of family life, of family support services, and of the nature of the interventions that families face from the perspective of youth, too. If approached from a service and systems reform perspective, the subfields of disability (e.g., brain injury, mental health), and by environment - employment, home living) must be addressed.

***Keywords:** family support, rehabilitation, social support, independent living, family coping, compliance, developmental disabilities, mental health/illness, substance abuse, behavioral supports, chronic illness*

***Citation:** Crittenden, P. (1990). Toward a concept of autonomy in adolescents with a disability. __Childrens' Health Care__. Vol. 19(3), 162-168.*

Summary:

The article begins with a discussion of autonomy and its changing definitions as reflected in literature trends in special education and on the development of non-disabled adolescents. The authors review the status of literature on the locus of control, coping strategies, supportive networks and attachment relation-ships which they define as critical aspects of autonomous behavior. The article than examines these areas within the "family context" as defined in the family systems and family therapy literatures with primary model elements of adaptation (process variable) and cohesion (process variable) mediated by (quality of family) communication.

The proposed model "for the development of autonomy" is defined by two developmental processses: accceptance of responsibility for one's own behavior and for making decisions *regarding oneself, and development of a set of supportive relationships consisting of: 1) transformation of the parent-child relationship in the direction of mutuality; 2) establishment of a peer network; and 3) the development of reciprocal peer attachment to replace the parent-child relationship as primary. However, the author also cites Brofenbrenner's (1979) social ecological theory as a framework for understanding other influences on the child's development. The author concludes by stating that "empirical support for the theoretical model offered here could substantially affect service delivery for individuals with disabilities."*

Analysis:

The author defines autonomy in terms of individual's capacities to take responsibility for their own behavior, to make decisions regarding their own lives, and to maintain supportive social relationships. The authors also cite a significant shift in studies toward adolescents' decisionmaking capacities, acceptance of responsibility, transformation in the parent-child relationship toward greater mutuality, and the importance of peer relationships instead of individuation and independence. However, the author's integration of the family systems and therapy and adolescent literature results in a proposed model which appears to be heavily weighted toward the family dimensions (e.g., "Families should take an active managerial role in all aspects of service to their children.") In relationship to adolescents with significant disabilities, the authors also rely upon the goal as being independence from assistance which effectively excludes these youth with significant disabilities.

Contribution to Conceptual Model:

In relationship to adolescents, the authors have taken the important model development steps of attempting to integrate knowledge from the perspective of adolescent development with professional perspectives about families, and to propose a model to resolve some of the tensions involved. It is one of the few articles which explicitly discusses the independent living model also within these dominant family contexts.

Keywords: *personal autonomy, independent living, adolescents, assistance, locus of control, coping strategies, transition, attachment, supportive (social) networks, family systems; family theories*

Citation: *Blum, R., et al. (1993). Transition from child-centered to adult health-care for adolescents with chronic conditions.* ***Journal of Adolescent Health Care****, 570-576.*

Summary:

The purpose of the paper was to highlight transition issues faced by the teenagers and young adults with significant chronic illness or disability. Citing the difficulties that some youth face and the lack of information on "model programs", the authors state that there have been no controlled studies of transition models (and no systemic efforts to analyze them) with unclear criteria for success. Describing the barriers in transitioning from the pediatric to adult health *care models, the authors highlight the fact that the "pediatric model that focuses on the parent may avoid critical adolescent issues such as sexual and reproductive health care, substance abuse, risk behaviors, vocational counseling and independent living."*

After reviewing the assumptions related to transition (E.g., "health transition;" life transitions in work, community and school), four key elements are noted: professional and environmental support (E.g., differential support by age), decisionmaking and consent (responsibilities of health providers and parents to support decisionmaking skills), family support (negotiating and renegotiating boundaries between supervision, autonomy, and independence), and professional sensitivity to the psychosocial issues of disability (adolescence as reflecting distinct issues from pediatric or adult health care).

The article proposes specific research questions for further study (E.g., What are the most appropriate outcome measures for evaluative research?) and concludes with recommendations from the Society for Adolescent Medicine regarding federal funding for model transition, federal research funding for adolescent-focused projects, evaluation of transition models across "spectrum of chronic conditions", collaboration between medical societies and industries (e.g., health insurance industry), and inclusion of transition in the professional education of medical students.

Analysis:

With the high rates of survival of children with chronic disabilities into adulthood, the authors offer an excellent introduction to the status of transition from a health care perspective. The article is remarkably consistent with approaches to the transition from adolescence to adulthood, yet varies from special education/vocational rehabilitation transition models which have tended to rely upon narrow definitions of adulthood and adult community life, with less attention to the nature of adolescents and their regular growth and development. framework.

Contribution to Conceptual Model:

One central message is that adolescents continue to live in a society where health care and services are organized around the needs of children and adults, which remains a central concern. Transition continues to be driven by professionals in education and vocational rehabilitation, which substantially effects the movement to adult life (which does not generally reflect the background of their disciplines). The reframing of family support to the emphasis on boundary negotiations is useful in moving toward service approaches based upon adolescents' own life determinations. In particular, the movement from the "pediatric model" offers some instructive parallels with "family" service models, especially in situations where the adults are at high risk of being treated as children or of being judged unable to make their own decisions (e.g., children with mental retardation, brain injuries, emotional disturbance).

***Keywords:** transition, adolescent health care, chronic disabilities, pediatric health, support, decisionmaking, family support, education, model programs, outcome research, policy,* *evaluation research*

Citation: *Minnesota Developmental Disabilities Council. (1992). Shifting patterns. Minneapolis, MN: Author.*

Summary:

Based upon a national survey of "best practices in empowerment and self advocacy," this paper describes shifting patterns related to individuals with disabilities and their families. Prepared for policymakers through a grant from the Administration on Developmental Disabilities, the survey included contacts with the developmental disabilities councils, the university affiliated programs, and a major consumer/parent organization in each state.

"For purposes of this study, empowerment is defined as processes whereby individuals achieve increasing control of various aspects of their lives and participate in the community with dignity." The themes were: career vision ("Key: supported employment), partners in policymaking ("teaches individuals with disabilities and family members to be community leaders"), parents as casemanagers ("improved by informed decisionmaking"), personal futures planning ("create a more desireable future for...the individual's journey toward a better future"), vouchers ("given the responsibility, authority, money and ability to buy what they want, need and prefer"), youth leadership ("cooperative efforts of and friendships among youth with and without disabilities"), and people first ("seen as capable of representing their own interests and exercising their own choices").

Analysis:

The paper contributes toward the creation of new patterns in community life, and in the movement away from service and program-oriented approaches to the lives of children and youth with disabilities [56]. The paper is excellent in raising and bringing to the forefront several themes and/or movements which have received inadequate attention in the field of developmental disabilities.

However, in this context, several of the highlighted themes continue to be based upon particular views of the relationship among parents, their children and services which may not be universal and in some instances, may not be healthy "models" (e.g., parents as casemanagers, including for adults[57]). Youth leadership is framed as cooperative efforts which assume an

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[56] *The authors attribute the "shifting pattern" in beliefs and attitudes: individuals, services and professionals, and community to the Cornell Empowerment Project.*

[57] *The model of parent or family casemanagement has received growing attention as an innovative service delivery model; see also, earlier discussions, (e.g., Intagliata, Willer & Egri (1988). The role of the family in delivering casemanagement services.)*

*equality, respect and environmental context which may not currently exist. While highlighting People First, several areas still place decisionmaking primarily in the hands of others (e.g., life planning **for** the person) and assume the future will be focused on program models (e.g., supported employment).*

Contribution to Conceptual Model:

In the context of PAS, all of the self advocacy and empowerment areas are directly relevant to the development of user-directed service (and/or community) approaches or models. In particular, the promotion of service models which may change the nature of the relationship between parents and their children (e.g., parents as casemanagers, vouchers), between service providers, parents, friends and children (e.g., personal futurres planning), and children with each other are critical. In the area of youth leadership and determination, the report suggests (p.22) an excellent range of school partnerships, outdoor leadership programs, and community occassions and places which are underutilized avenues.

Keywords: *Career, employment, self advocacy, youth with disabilities, youth leadership, developmental disabilities, casemanagers, financing (vouchers), empowerment*

Citation: *Baughan, J., Brown, P. & Uhl, M. (1993). Finding the fun: The importance of play for parents*[58]*.* __*Exceptional Parent*__*, 2396), 32-34.*

Summary:

In a tone of lightness, the article describes the neglected art of playing, which has been lost for many adults, including parents of children with disabilities. Trying to instill a self permission to "develop a daily habit of play," the article shares some ideas about "how to find fun": let go of time (join in with our child), be spontaneous ("the voice that is telling you what you really want to do, with or without your child"), maintain a sense of humor (relearn how to be silly), take some risks (be a participant), and keep a positive attitude.

Analysis:

The article is a parental permission one: it's okay to be good to you, to have fun, to take time to enjoy the things you want to do, with your family and with you. The message of the article is one of life, and of enjoying your children, not one of escaping from their care or burden or of a life filled mainly with guilt, appointments, and responsibilities. The context is critical for moving from concepts of respite as defined as relief from the burden of caring to ones

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[58] *The review of* __*Exceptional Parent*__ *was notable in its inclusion of articles on play, and on social activities such as proms, summer camps, adventures, school field trips, community places like zoos, playgrounds, birthday parties, costumed imitations, sleepovers, cards and board games, fitness, team sports, and on relationships (e.g., friends to play with).*

of children and youth living their own lives. The article, however, does present the parent's way of looking at this, which may be seen very differently by the child.

Contributions to Conceptual Model:

In the process of service translations, the spirit of living, in fun (recreation) and in home living are often being lost. For example, the concept of spontaneity, highighted in this article is often blocked by the service mechanisms which are designed not to allow these things to occur, and which are seldom considered as an essential part of being a child and of learning to be an adult within the special education processes in schools. The article also sets an important framework for the part of the change in family dynamics related to moving away from seeing children as "burdens."

Keywords: *recreation, play, friendships, social relationships, parenting, respite, attitudes*

Citation: *Resnick, Litman & Blum. (1992).*[59] *Physician attitudes toward confidentiality of treatment for adolescents: Findings from the Upper Midwest Regional Physicians Survey. Journal of Adolescent Health Care, 13, 616-622.*

Summary:

The "provision of confidential medical services to adolescents is an enduring health policy issue in the United States, and the focus of policy statements by several professional medical organizations." In addition to the discussion of these issues, the article reports on an "indepth examination" (survey) of physician practices, attitudes, and beliefs toward adolescent patients in 5 states in the "upper mid-West." The most salient findings are that three-quarters of the respondents favored confidentiality in youth services, that adolescents had special and unique needs which distinguished them from other age groups, and that those physicians who assessed themselves as higher in addressing sexual issues also were more proportionally in favor of confidentiality in youth services. The article also reports findings based upon year of licensure, adequacy of training in interpersonal and sexual issues, and training in traditional medical problems of youth. The article begins and concludes with a discussion of the status of policy and its implications.

Analysis:

For purposes of PAS, this article was selected primarily due to its clarity in its introduction and discussion regarding confidential medical services as an enduring health policy issue, particularly as it relates to adolescents. The article reviews the position statement of the

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[59] *See also, articles on decisionmaking, for example, Lantos, J. & Miles, S. Autonomy in Adolescent Medicine: A framework for decisions about life sustaining treatment. Journal of Adolescent Health, 10, 460-66.*

American Association of Pediatrics also endorsed by other national associations which encourages adolescents to involve their parents in treatment decisions, asserts the primacy of the physician-patient relationship, the responsibility for health care professionals to state the conditions under which confidentiality would be abrogated, and in serious health threats, not having needed services impeded.

The article reviews legal constructs in contractual relationships with teenagers[60] *which have evolved to "facilitate the provision of confidential health services to adolescents (e.g., emancipated minors" as defined by financial or domiciliary independence or by the fact of preteen parenthood; the "mature minor doctrine" which stipulates that certain adolescents have sufficient maturity to make health decisions; Supreme Court decisions upholding the legal access to reproductive health services). It also explicitly discusses the concept of "best interests of the child" as most vocally expressed around the issues of adolescent sexuality, the breaching of confidentiality when "individuals are judged incapable of making informed decisions on their behalf," and dilemma of confidentiality in situations with potentially adverse consequences.*

The article also notes that legislation has been enacted in all states and the District of Columbia which allows youth to seek health services within narrowly defined areas, and cautions against the enactment of blanket legislation regarding confidentiality.

Contributions to Conceptual Model:

The research findings on training can be integrated into the work with physicians on the incorporation of these concepts into adolescent growth and development training. The policy implications on contractual arrangements (e.g., youth-to-youth, mentoring), youth confidentiality (especially in controversial matters), and confidentiality statutes, including those effecting determination of competency ("incapable of making informed decisions") are the most relevant.

Keywords: *adolescents, physicians' training, health care, confidentiality, health policy*

Citation: *Watson, S. (1993). Public responsibility, personal choice: Providing personal assistance services in Montana. Boston, MA: Harvard University.*

Summary:

The case study of the personal assistance program in the state of Montana describes the history of the program since its beginnings in 1977, the "national context" in terms of the history of independent living and the use of the Medicaid waiver and personal care option, and the administrative system in the state for the program. The major subject areas of the case study were:

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[60] *See also, statement on the protection of child and adolescent workers, March 1995, American Journal of Public Health, Vol. 85(3).*

* budget tradeoffs (e.g., client frustration with services; some job scheduling flexibility; employee wages),
* fundamental disputes between the administering agency and advocacy community on client "control" of program (disagreement over whether a problem existed based on satisfaction survey responses, distribution of advocates (empowered by vr) around the state, design for selecting, managing and scheduling attendants, abuse, protection and responsibility),
* attendant duties (struggle to control the person, regulatory restrictions on attendants as a symbolic issue, advocacy for more supervision and monitoring);
* using family members (federal rules as prohibiting payments to families, personal morality violations, advocacy efforts in other states to be used as models);
* Native Americans (34,000 people on seven reservations "tribal ways" and getting things done through IHS;
* ongoing question of trust ("reluctance to challenge authority," "pathological gratitude");
* nature of small towns (small state; hold jobs long time; change strategies, advocacy and media).

The case study ends with what the state decided to do with the program. Teaching notes on the case study describe the fundamental dilemmas as fiscal (fund allocations and agency constraints communication) and control (client control over professionally managed programs) with other issues to explore (e.g., messages of government about lifestyles). The teaching notes use basic questions to frame discussion in terms of contractors, complaints, taxpayer and public official responsibility, governments' assessment of quality of life, perceptions of diverse constituencies, federal financing role).

Analysis:

The case study attempts to frame issues regarding a state program from the perspectives of people using a traditional policy/social systems analysis of the issues facing people with disabilities in their lives ("how government works"). The case study integrates "client" and "advocacy" issues within this existing framework. The teaching notes are helpful as a framework for discussion within the assumptions of "formal" government as it "works" today as perceived at the service level.

In regard to substantive issues on personal assistance services (in relationship to people with mental retardation, mental health, and brain injuries), the case study does not analyze "personal assistance" in the state, but is focused upon one program primarily designed for people with physical disabilities. It is not possible to judge the validity or reliability of the information, since the sources and methods are not described. The case does not specifically distinguish between children, youth and adults with disabilities.

Contribution to the Conceptual Model:

The major contribution is in the importance of the interpretive and analytic frames in pursuing personal assistance services in a context where government is assumed to "work" in certain ways. Specifically, the case study raises the issues of the ways in which advocates influence government, government's perspectives on lifestyles, personal morality and governmental interventions, and government's assessment of life quality.

Keywords: *personal assistance services, personal care, public policy, public financing, rehabilitation, social services, independent living, workforce/employment, abuse, advocacy, service delivery systems*

Appendix A:

In relationship to the policy model proposed by Simi Litvak of World Institute on Disability (1993), the reviewed literature contributes the following:

Systems/policy[61]*:*

Service designs and policies within these categorical disability areas (mental health, mental retardation/developmental disabilities, traumatic brain injuries) are still primarily based upon the concept of a "continuum" of services (with the underlying legal principle of the least restrictive environment). One implication is that people with the most significant disabilties are excluded from regular opportunities in the community (e.g., access to 24 hour support services in their own homes).

Emerging designs in support services are based upon the concept of "nonrestrictive environments" (with intensity of services and restrictiveness, for example, not tied to readiness, a setting or level of disability) while the emergent pas systems remain based upon the legal principles of LRE and the principles embodied within the Americans with Disabilities Act (ADA).

Coherent public policy in relationship to the changing systems and legal principles within disability has not occurred, and policy on economics, education, social, transportation, health care, and employment have not yet been framed as applying to all citizens. For the future, public policy and service designs based upon youth development, as distinguished from youth programs must be shaped to guide the futures with youth with disabilities. Prevention, in a broadened sense, also holds some promise for service system (as distinguished from community) forms of assistance.

Access:

Access issues in these sets of literature are framed as service access limitations by:
- *age group (e.g., youth or adolescents, high-risk children),*
- *disability group (people with brain injuries),*
- *families or by children, youth and adults with disabilities,*
- *significance of disability (e.g., unable to manage own care).*

Primary types of access adressed are:
- *universal access, primarily in areas like housing and health care,*
- *as information access (especially by youth as opposed to access by only parents or guardians),*
- *service access: communication (e.g., interpreters) with some efforts to define access and*

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[61] *See, Racino, in press, 1996 for personal assistance (PAS) and public policy.*

barriers from the perspectives of parents and professionals),
- *income access (based on family, agency and system financial resources),*
- *cross-disability (with some efforts to distinguish across disability groups) and cross age (transition youth to adult services).*

Eligibility:

Eligibility issues for pas (in integrated system designs) require analysis across diverse funding sources, some of which are based on program of entry (e.g., workers' compensation), categorical (disability group) community services initiatives (e.g., targeted Medicaid waivers), federal/state demonstrations (e.g., pas demonstrations funded by the Administration on Developmental Disabilities), federal disability law as applied to programs and services (e.g., IDEA), state funded programs (e.g., family support) or national health care (e.g., movements to managed health) or social (e.g., family and employment policy) reform.

These sets of literature described the extension of service eligibility to people with brain injuries, the exclusion of people within certain categorical groups in states from pas services (e.g. psychiatric disabilities), prohibition of payments to families (Watson, 1993), the federal requirement for pas services to be available to all categorical disability groups and the need to review state implementation (Smith, 1994), indirectly raised the issue of pas for, by and with youth with disabilities (e.g., within the "family home"), and discussed eligibility within the traditional pas systems (in contrast to the mental retardation and developmental disabilities, mental health, brain injury systems).

Assessment:

Service (eligibility, planning, outcome) assessments continue to be primarily deficit-based, with a movement toward functional (and environmental) assessments. Life planning processes and emergent forms of services and designs, often merge with standard forms of revisions in assessments (by extending eligibility requirements, facilitating service access, or extending eligible service categories). Universal eligibility and access have tended to be framed within context of health care reform. As reflected in these sets of literature, services (and clinical) assessments permeate the professional disciplines with this way of thinking further supported by research and service outcome based assessments (inclusive of quality of life outcomes).

Services limitations:

Vast discrepancies exist between eligibility among the states, and also across specific federal programs which may include personal assistance services (with eligibility by disability group). Most state studies have been directed toward the federal program type or initiative versus study of assistance across the disability types and groups (which tends to marginalize certain groups and services). Waiting lists for community services remain a major public policy problem in the states.

Expansion in types of tasks (e.g., assistance with emotions), areas (e.g., transportation), the roles of assistants (e.g., coaches at work, life coaches), availability in diverse environments (e.g., leisure and recreation), adaptations as substitutes for paid assistance, and limitation on service models (e.g., agency versus self-directed approaches) are the primary service limitations (by service type) addressed.

Workforce issues:

Workforce issues, in terms of shifting employment in the US (other than cultural changes) and systemic issues in the national cadre of personal care assistants, were not specifically discussed[62]*. An analysis and national (state-by-state) data collection, at least at the equivalency of work force analyses in mental retardation (or segments of the human services workforce) were not in place related to PAS. Opportunities exist, as increasing numbers of institutions close, to also shift resources to more user-directed forms of pas.*

Common problems with pcas and pca systems were the lack of availability of pcas, turnover (of personal assistants), lack of emergency back up systems, personal liability (insurance) with self-directed assistants, qualifications and training of pcas, lack of career ladder, decent wages and benefits, devaluation of pcas in professional environments, negotiation of conflict, employee protections of pcas, and protections of and for pca users.

Liability issues:

This set of literature did not specifically address liability issues, other than implicitly related to contractual relationships with teenagers and the rights of minors and their parents (for example in health care). Other potential issues of liability implied were related to guardianship, involuntary commitment, sexual and associational rights of adults, violations of the ADA and IDEA, and abuse in agency pas. Common liability issues, actual and perceived, between agencies and service users which affect eligibility and termination were not raised (e.g., people moved to institutional or congregate settings due to perceived agency risk as distinguished from risk for the person).

Service quality:

Though direct references to service quality were not made in most of these sets of literature[63]*, service quality was framed in diverse ways, increasingly in the context of the life*

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[62] *Workforce analyses by categorical disability group (mental health) and national (state by state) human service worker data (e.g., developmental disabilities) were reviewed in the "categorical" area.*

[63] *See quality of life (service) standards, Options in Community Living, and Goode's quality of life (concept which may include service quality as part of seconday analysis) for persons with*

quality of the person and new paradigms (support/empowerment):

- as reflecting the principles and outcomes of independence, productivity, personal autonomy (personal choice), and universal accessibility (zero reject);

- as consistent with the frameworks of independent living, family-centered (care), community (re)integration, community inclusion, mutual support and self help, youth leadership, (community) health and wellness, and/or family support[64];

- as being in accordance with the principles underlying the Americans with Disabilities Act, consumer, employment and economic rights, and the Individuals with Disabilities Act (IDEA);

- as responsive to consumers and/or parents (caregivers); as involving youth and adults with disabilities and/or their families; as directed (or controlled) by the employer (with a disability), as promoting consumer sovereignity;

- as reflected in partnerships (community, school, parents, professionals, individuals with disabilities), collaborations, and associations, alliances, youth and consumer movements, and political action (advocacy);

- as being holistic, community (based, integrated, or of community), ethnic and culturally responsive, promoting social acceptance and social relationships, inclusive of individuals and families at-risk;

- as enhancing or promoting positive life outcomes as the person defines them, versus other articles which reflect "client outcomes" as defined by professionals (e.g., where people live, the activities people participate in);

- as being well "managed," with access to professional services, and community (individualized and flexible) supports, in accessible environments, and inclusive of consumer-operated services ("membership's self-defined needs");

- as involving people with disabilities in all aspects of service design, planning, implementation, evaluation and research.

This literature also discusses service quality in the context of professional paradigms in

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disabilities (1994).

[64] *For the family analyses, see Dunst (1993). Principles: enhacing a sense of community, mobilizing resources and support, shared responsibility and collaboration, protecting family integrity, strengthening family functioning, and proactive human service practices.*

rehabilitation medicine, adolescent health care and public health (which overlap some of the same principles in areas such as family support).

Long term services coordination[65].

Long term services coordination must be examined from diverse points within and outside the service systems structures. The only significant themes or ideas in this review on long term service coordination were:

Service coordination. *Parents (relatives and sometimes individuals themselves) as casemanagers, the management responsibilities of professionals especially in relationship to people with significant disabilities, casemanagement as an accepted, standard practice, and service coordination as an agency interrelationship function. Service coordination (and service brokerage) are also part of the emerging models of agency pas (e.g., in community living), and of natural supports approaches (e.g., employment).*

Other ways of thinking about service coordination also appear in this set of literature. Sometimes people (e.g., psychiatric survivors) have experienced casemanagement as controlling and new "approaches" (e.g., casemanagers having money available for flexible use by their clients) as forms of coercion. Other ideas were to move away from monitoring and training roles for personal assistants; or to have personal assistants as substitutes for casemanagers with assistants being employed by the person.

Structures for coordination. *Selected integrated systems approaches (state-focused) were included in this review; these typically involved a primary categorical group with coordinating relationships at the state generic departmental level or contracting relationships at the local levels. Two other forms were integrated services coordination branching from the schools, and forms of youth coordination through coalitions and inter-departmental relationships.*

No new forms of revised state structures, based, for example, upon local changes (e.g., agency, voucher-reimbursement programs) were described. None of this literature addressed the barriers to service integration as identified in the GAO report (review of twenty years of integration). The literature was not primarily focused on (national) health care reform, though sometimes financing through health care and existing structures and politics influenced the disability specific literature (e.g., increased interest in managed care).

Consumer control:

Consumer control are interpreted as the degree of direction (management and coordination) of (paid and unpaid) services, employment (inclusive of selection, hiring, and/or

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[65] *This review did not specifically include casemanagement, service coordination or service brokerage, which as referred to in the WID grant application, is voluminous.*

termination) of the (paid or unpaid) assistants, control of one's own life (direction, relationships, activities), and direction of services. Most service concepts reflected supports or services organized around service users, sometimes framed as collaboration, negotiation, partnerships or mutuality (mutual support, mutual relationships) within program contexts.

Consumers (i.e., recipients of services, clients, service users) are interpreted to mean interchangeably families, parents, adults with disabilities, youth and/or children with disabilities. Control (and related concepts such as autonomy and independence) basically meant (formal) professional control, the professional transfer of control to the person as they gained "competency", the professional transfer of control to a surrogate, parent or one who acts on behalf of the person, or control by the individual and/or the family (generally within the program context).

"Control" by people with disabilities was described primarily in the pas and independent living literature with approaches to user-directed pas also in the categorical literature. The articles discuss ways of thinking about "choice" and "empowerment (e.g., Guess' on reframing communication and control); new approaches to consumer control in the area between self-direction and direction by others of services are suggested in other literature and policy/practice documents. Only two articles attempted to differentiate and analyze the views of professionals (service providers) from those of service users.

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